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I've said before that every craftsman
searches for what's not there
to practice his craft.

A builder looks for the rotten hole
where the roof caved in. A water-carrier
picks the empty pot. A carpenter
stops at the house with no door.

Workers rush toward some hint
of emptiness, which they then
start to fill. Their hope, though,
is for emptiness, so don't think
you must avoid it. It contains
what you need!

Dear soul, if you were not friends
with the vast nothing inside,
why would you always be casting your net
into it, and waiting so patiently?

Poems by Rumi VI (1369-1420)
(Rumi, Online)

UNIVERSITY OF CALGARY

**Gift of Allah: An Ethnographic Study of
Mothers who Care for Children with Disabilities**

by

Saira M. Zaidi

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATES STUDIES
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ABSTRACT

Data for this ethnographic study were collected over a period of two months in Islamabad, Pakistan. This study explored the daily life experiences of eleven mothers who cared for children with disabilities in a low socioeconomic setting.

A holistic perspective of caregiving beliefs and practices is presented including eight themes that emerged from the mothers' narratives: Gift of Allah, hopeful of cure, motherhood, caring, daily routines, health, *pir/faqueer* and social support. Mothers' acceptance of the child's disability and continuous commitment to care with very limited opportunities were phenomena that pervaded their life experiences.

This study contributes to the small body of cross-cultural research on caring and Islam. Furthermore, it provides insight into women's caring that is different from current feminist analysis. Caring provides mothers with purpose through which they find fulfillment by taking on responsibilities of care. The mothers embraced their child as a gift from Allah that enables them to cope and fulfill their motherhood role. Another identified belief is that Allah would not have tested them beyond their capacities, and that they will be rewarded both in heaven and here on earth

Social development requires that societal values change in such a way that women and children can access education and better health services. The first step on the path to reducing the high prevalence of disabilities and help in caring for children with disabilities would be to provide community services and develop caregivers' personal resources.

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Chapter 1

INTRODUCTION

The concept of caregiver burden was strange and almost incomprehensible to me before I moved to the West. How could caring for loved ones be a burden? In my experience, caring for someone arises out of a bond or a relationship that originates in personal familiarity and obligation. In Pakistani society, caring for parents reflects familiarity, reciprocity, and obligation. Caring for children is grounded in the love and obligation that comes from being a parent. Mostly, children and their spouses care for elderly dependent parents. However, parents do not have to be old or dependent to be cared for; simply by virtue of their relationship, children care about them. Similarly, people care for their children with disabilities because of their obligation and love. Although caring for children with disabilities entails more hardships and sacrifices, that fact does not alter the norm of the parent-child relationship. Furthermore, in Pakistani society these values go beyond caring for one's immediate family members to encompass extended family members.

This endeavor is my attempt, as a feminist, to understand the concept of caregiver burden from the perspective of mothers who provide care for their children with disabilities, that is in the context of rich, long-lasting familial relationships (Abel, 1991). The concept of caregiver burden is not to be found in Pakistani literature. Turner and Cherrin (1998) assert that Pakistani families provide almost complete economic and social support to their members.

That women perform the majority of the work of caregiving is not unique to Pakistan. As many feminist scholars such as Baines, Evans, and Neysmith (1997), Abel (1991), Neysmith and Aronson (1993), and Allen and Walker (1992) have asserted, Western women have traditionally provided care for ill or disabled relatives at home. Moreover, the literature indicates that most children with disabilities are cared for by their mothers and that the overwhelming responsibilities for care can create resentment and guilt (Parks & Pilisuk, 1991). Pakistani families have been caring for their aged, sick, and disabled for centuries. The incidence of disabilities in Pakistan is exceptionally high compared to that of surrounding countries in Asia (Mumtaz & Shahid, 1987). This inquiry will explore the current realities of low socioeconomic class in a region of Islamabad, Pakistan, to ascertain how mothers in that situation care for their children with disabilities. Of interest will be how they utilize their personal and interpersonal resources as well as their cultural and religious belief systems in coping with the needs of their disabled children.

This thesis arises from a professional interest in working with children with disabilities and their families from 1988 to 1997 in Pakistan and the United States. I attempt to advance insight into this issue by incorporating voices that have been previously unheard (Allen & Walker, 1992), those of mothers who care for children with disabilities, and to understand their worldview about children, caring, and family in their particular contexts. My focus on this topic is motivated by three factors: close involvement in the special education field, exposure to the concept of

caregiver burden in social work education in the West, and a desire to understand caregiver burden from my own cultural perspective.

My career involvement in the field of disabilities started during the 1980s, when the first Special Education programs were introduced in Islamabad, Pakistan. This provided me with an opportunity to learn about disabilities and to notice that parents were wary of the new Special Education programs. During this period, several areas of professional knowledge made substantial advances in Pakistan. These advances included:

- understanding the processes by which children with disabilities acquire social skills;
- communicating with families and acknowledging their vital role (Miles, 1995); and
- further understanding of disabilities and caregiver needs.

Later, in the United States, I worked for Special Education programs in Virginia, which exposed me to western mental health perspectives and systems. This opportunity provided me with many answers regarding mental health diagnostic criteria and specific behaviors of children with disabilities.

Studies in social work then exposed me to the concept of caregiver burden for the first time. Further learning and understanding about the concept of caregiver burden came from an intern placement during my graduate program. This experience made me examine my own societal values regarding caring and led to confusion and curiosity. One purpose of this endeavor as noted above, is to understand the concept of caregiver burden from my own religious and cultural context.

Pakistan is a developing country, located in Southeast Asia. The population of the country is estimated at 143 million. Pakistan is primarily a rural-based

country, with 67% of its population living in rural areas and 35% in urban Pakistan (Farhat, 1999).

The economy is predominantly agriculturally oriented. Cultivated land stands at around 33 million hectares, irrigated through a novel canal irrigation system noted for its design and architecture. The major crops are cotton, wheat, rice, sugarcane, pulses, oil seeds, vegetables, and fodder. The country's economy is however, moving toward industrialization; industry is becoming another sector that employs a sizeable population (Farhat, 1999).

Pakistan is predominantly a Muslim country. The view of Pakistani society as orthodox and fundamentalist does not reflect the experience of the majority of the population (Farhat, 1999). Pakistanis are practicing Muslims, but the majority of the female population does not observe *pardah* (the veil) literally. Nonetheless, the concept of *pardah* is apparent in the gender segregation that divides public and private spaces, with women expected to stay in private areas (Khan, 1999; Sinha, 1991). Presently, Islamic scholars have, through Islamic law, restricted some Pakistani women via seclusion and *pardah* (Esposito, 1998).

The social structure of Pakistan is based on patriarchy. Boys are regarded as assertive, active, and aggressive whereas girls are expected to be submissive, passive, domestic, and sacrificing. Males usually dominate the family and deal with the outside world; women are generally secondary and deal with matters within "four walls", the term used to refer to the special private places for women, such as their own homes or those of their extended family. Most mothers spend the bulk of their lives physically within these walls, going outside only when there is a substantive

purpose. There is a separation between most aspects of men's and women's lives. Women usually interact only with closely related men, in a relation of servitude (Farhat, 1999; Tinker, 1998).

Due to economic hardship, women's roles have been changing. Previously women have not been expected to work outside of their homes (Mumtaz & Shahid, 1987; Tinker, 1998; Weiss, 1991; Weiss, 1998). But international agencies in Pakistan are now encouraging women to join the workforce and become partners in economic and social development. In these times of growing economic pressures high inflation and increased cost of living some women are simultaneously raising families and working outside their homes to earn a living.

The goal of this research is to learn from women themselves about their perceptions, within a particular religious and cultural context, of caring for children with disabilities. In the remainder of this chapter, the following topics will be presented: statement of purpose; research questions; significance of the study; and an overview of the remaining chapters.

Statement of Purpose

The purpose of this qualitative inquiry is to expand the body of knowledge concerning caregiver burden by means of listening to the voices of mothers who care for their children with disabilities. The current study focuses on women's context, her worldviews, and how religious beliefs affect her experience of caring for children with disabilities and her role as a mother. The goal is to understand the influence of cultural realities on these mothers, and the way they use their cultural realities to

balance caregiving responsibilities and the demands of multiple other roles with the very minimal community resources available.

To accomplish these purposes, a systematic effort was made to collect information from mothers of children with disabilities regarding their daily life experiences. The anticipated outcome of this inquiry is to gain insights into what supports and services are required in Pakistan for mothers who care for children with disabilities.

Research Questions

The primary research question of this study was, **“What are the daily life experiences of mothers who have children with disabilities?”**

Significance of the Study

This was a timely endeavor. When this research commenced in 1999, there were no programs designed to address caregiver needs (e.g., self-help, support from schools). Programs to alleviate poverty or provide education and health in Pakistan are often funded by a number of nongovernmental organizations (NGOs) with foreign resources. Providing services for caregivers would fall under the areas of both health and education. That is, health funding with a population-specific allocation is needed to support and provide facilities for caregiver programs. In addition, education funds are required to improve caregivers' awareness of mental health issues as well as to educate the general population about disabilities. A number of recommendations concerning some of the issues under investigation will be made in the concluding section of this study.

As well as contributing to recommendations that were made for Pakistan, this research makes contributions in two areas: (1) to the general body of knowledge about caregiver burden in Pakistani society; and (2) to social work practice and education.

Contribution to General Body of Knowledge

Three issues arise concerning the contribution of this study to the general body of knowledge: conceptual; methodological; and translation issues.

Conceptual issues. For the most part, women's work of caring has been conceptualized as burden by Western researchers. One reason for this is that most women (59%) in western societies work (Harlan, 1998); another is that the support and cooperation of extended families in Western societies is very limited due to extensive mobility.

Clausen and Yarrow (1955) defined the concept of caregiver burden in 1955, one decade after the end of World War II. That war had brought about radical changes in the status of Western women: historically, they also stayed home to look after the management of household and children, but during the war they were required to fill in gaps in the job market as men went overseas to fight the war. They thus gained financial status, and the discourse of equality became popular again as the second wave of the feminist movement crested (Harlan, 1998; Valentich, 1986). Thereupon the concept of burden emerged as a social construct in the Western literature.

In the cross-cultural literature, there are very few studies available that have not applied the concept of caregiver burden within developing countries (Kurian,

1997; Li-Tsang, Yau, & Yuen, 2001; Shyu, Archbold, & Imle, 1998). The studies that have associated caring with burden (Bhat & Gauba, 1978; Ilango, & Nirmala, 1992; Pai & Kapoor, 1981; Singhi, Goyal, Pershad, Singhi & Walia, 1990; Verma, 1978) have taken a positivist approach to research, using western scales to measure caregiver burden. However, the mothers in these studies were groomed to be mothers and “kin keepers” within four walls. Their religion provides them higher status when they become mothers (Hashmi, 2000; Jawad, 1998; Khan, 1999; Rouf, 1977). Their religious beliefs and cultural realities are very different from those of Western society, and so it is critically important to explore the caring from their perspective, using a holistic paradigm.

Methodology. Many different qualitative methodologies, such as phenomenology, case study, and naturalistic inquiry, among others, have been used in exploring the concept of caregiver burden with different age groups, ethnicities, and disabilities. However, this is the first study to use ethnography as a methodology to explore caregiver burden in a non-Western culture with an Islamic contextual framework. Ethnography deals with cultural awareness and identifies the issues of a certain population. This ethnographic study was designed to illuminate not only the context but also the rationale of cultural behaviors from the respondents’ point of view. This investigation offers an overview of local belief systems and cultural values, which provide a clear understanding of the daily life experiences of respondent mothers of children with disabilities living in Pakistan.

As mentioned earlier, caregiver burden in cross-cultural literature was reported by using positivist approaches for inquiry in the 1970s and 1980s (Bhat &

Gauba, 1978; Ilango, & Nirmala, 1992; Pai & Kapoor, 1981; Singhi, et al., 1990; Verma, 1979), however, more recently a narrative used in investigating the concept of caring (Kurian, 1997; Li-Tsang, Yau, & Yuen, 2001; Shyu et al., 1998). Over time, then, a greater sensitivity to the cultural context of caring has influenced a change in methodology. The present study is consistent with the more recent methodology.

Ethnography raises awareness regarding cultural practices and, therefore, initiates a dialogue for social change (Munhall & Oiler, 1986). By understanding what it is like to be the mother of a child with a disability in the context of that mother's culture, health, and education, professionals could become more sensitive to the needs of such mothers and their families (Creswell, 1998). The current study provides a picture of societal values that may need to be challenged to further social development and, with it, social change for persons with disabilities and their caregivers in Islamabad, Pakistan.

Many ethnographers are involved in studying their own culture (Chock, 1986). One of the ethnographic assumptions is that the researcher is an instrument who gathers, describes, analyzes, and interprets data (Creswell, 1998; Roper & Shapira, 2000; Streubert & Carpenter, 1995). A researcher, whether belonging to the same or a different culture, brings his/her own biases to the process of research, although these biases can be held in check by utilizing the techniques of reflexivity. Despite these biases, investigating one's own culture has a myriad of advantages (Al-Krenawi, Graham & Maoz, 1996; Bohannon, 1981; Chock, 1986; Greenhouse, 1985). Subjectivity vis-à-vis one's own culture is further discussed in Chapter 3.

Translation. An important element of cross-cultural ethnography is translation. Although the literature does not provide any guidance on this topic, ethnographic studies are usually conducted in a language that is not the mother tongue of the researcher. Language is made up of different phrases. Phrases, when translated, may lose their essence, and the same phrase with accompanied by variations in tone and gesture can have many different meanings. The method developed for this study to sort through the subtleties of translation is very basic, but some such methodology must be addressed. Translation method and issues are discussed in detail in Chapter 3.

Contribution to Social Work

The research findings of this study, first, add to social work practice in certain areas such as education and counseling of mothers, family members, and the general public. Second, the findings make it apparent that, to bring about changes in this field, social workers in Pakistan may need to be challenged to take up greater leadership roles in hospitals, clinics and schools. The third contribution is to raise awareness that social workers can influence social policy and/or program development by evaluating the situation, proposing policy or program changes, and implementing changes to meet the standards and goals of the profession: supporting populations in need and eradicating human misery.

Pakistani social work education has not focused on macro-level issues, such as community mental health services, or the development and implementation of policy and programs. The contribution of this study to social work institutions in Pakistan could be to enhance macro- and micro-levels interventions in three ways:

first, by introducing students to new health professional roles, second, by providing advocacy to people who are not aware of their needs; and finally, on the micro level, by utilizing assessments tools that are sensitive to the cultural and religious aspects of understanding caregiver burden and disabilities.

In the West, social work practice orients and manifests itself locally—at the community, municipal, provincial/state, or national level. International social work practice takes a broader view and works from a social development perspective of economic and political systems in developing countries. This study enables social workers generally working in mental health settings to learn more about the Islamic religious beliefs that influence Muslims. In particular, social work practice will benefit in the area of caring for the disabled by gaining an understanding of the Islamic perspective. There are a growing number of Muslims in Western societies, and many social workers in the field of mental health and caring work with this and other non-western populations.

Finally, this research contributes to the very limited literature in the English language on Pakistani society. The presentation of a conceptual framework that focuses on a setting not many westerners are aware of exposes them to a different set of religious beliefs and cultural realities that influence Pakistani societal values. As well, this research poses alternative explanations for concepts such as coping, caregiving, and role identity. In addition, it presents alternative methods of support, such as extended family and neighbors, in the absence of formal support networks.

Dissertation Overview

This dissertation is divided into six chapters.

Chapter 1. This introductory chapter offers essential background information as well as reasons for the selection of this particular research topic.

Chapter 2. The second chapter reviews the published literature, examining the findings and observations of previous researchers from conceptual and methodological points of view. The review focuses on the Western, post-modernist, feminist, and Pakistani literatures. In addition, Chapter 2 discusses the complexity of applying the available conceptual and operational frameworks to a non-Western culture. This discussion also raises some of the difficulties associated with drawing from the existing literature.

Chapter 3. Chapter 3 lays out the plan for the research design through the operationalization of concepts as well as identifying the *place* and the ways of *entry* into the setting for conducting ethnographic research. This section discusses sample selection, the importance of sample size, and the justification of the quantity and quality of the sample. Instrumentation is also discussed. Many types of documentation utilized in the process of recording data and data analysis are specified in this chapter. Issues regarding rigor of research, with an emphasis on conducting research in one's own culture, are also addressed. In essence, Chapter 3 attempts to simplify the many complexities of research by outlining and streamlining the process and procedures of research design for this study.

Chapter 4. Chapter 4 presents the findings derived from the data collection process and the data analysis. These are arranged thematically. First, demographic data are provided. Second, domains arising from the data analysis are introduced, described and defined. Third, themes are categorized from the domains. Finally, the

findings are elaborated on and embellished with quotes. To simplify complex, integrated concepts that overlap, figures are used with taxonomies for each domain. Photographs are used to tell a visual story of the informants' lifestyle. This presentation style is used to better facilitate readers' understanding of the mothers/caregivers' perception.

Chapter 5. The fifth chapter presents an interpretation of the data analysis. Three domains emerge; religious beliefs, intrapersonal domain, and cultural realities. The religious theme that emerged was “Gift of Allah”. In the intrapersonal domain there were two themes: hope for a cure and motherhood. In the cultural realities domain the five themes identified were caring, daily routine, health, *pir/faqueer* (faith healers), and social support. Several aspects emerged under each theme that sometimes overlapped and at other times conflicted. This chapter offers an analysis within the context of cultural and religious knowledge and appropriate social patterns of behavior. Hence, the analysis first presents the setting of the cultural norms and religious beliefs, and then places the narratives of mothers in their context.

Chapter 6. The final chapter discusses the research findings as well as strengths and limitations of the study. Chapter 6 also includes a section on the implications of the study's findings for research, education, and the practice of social work. This chapter concludes with recommendations concerning services for mothers and their children with disabilities.

Chapter 2

REVIEW OF LITERATURE

This chapter reviews and discusses the available literature on caregiver burden. Since the mid 1950s, the concept of caregiver burden has been recognized in the literature and measured in numerous ways. Initially, the notion of caregiver burden was associated with the aged; later it was applied to the mentally ill adult population. After a decade of discourse, the literature began to distinguish between subjective and objective perceptions of caregiving burden, and the concept became associated with different variables such as social support, stress, well-being, and gender and ethnicity.

This review examines both Western and Pakistani literature relating to caregiver burden. The first section surveys studies within the Western literature in order to better understand the concept of caregiver burden. No Pakistani studies directly relating to caregiver burden were located. In their stead, studies concerning disabilities and special education were used to provide the conceptual framework for the current research. The Pakistani literature provides the reader with a framework for understanding women's issues in the context of Pakistani culture and society. This review of Pakistani literature has been divided into two domains: contextual and conceptual frameworks.

I WESTERN LITERATURE

The purpose of this section is (1) to illustrate the depth of knowledge available in the field of caregiver burden;(2) to demonstrate that the current study

contains original research; and (3) to understand the ways in which caregiver experience do, or do not, transcend cultural, linguistic and political boundaries. Four aspects of the Western studies are considered:

1. Methodological dimensions
2. Differing paradigms: postmodernist and feminist perspectives
3. Review of qualitative and cross-cultural studies
4. Theoretical framework

I. Methodological Dimensions of Caregiver Burden

Arrays of methodological dimensions are found in caregiver burden studies.

Two important dimensions are conceptual framework and operational framework.

Conceptual Framework for Caregiver Burden. In the social science literature, different terms such as "burden," "caring," "caregiver burden," "caretaker," and "parental stress" are used to define caregiver burden. Social work dictionary describe a caregiver who can be a relative, friend, or a paid aide who meets the needs of a dependent person (Baker, 1996). The literature as a whole spans a very broad definition of caregiver burden, defining the **subjective and objective** impacts of this burden and examining potential **gender differences**.

Claussen and Yarrow (1955) along with Grad and Sainsbury (1968) were the first to present the concept of caregiver burden. This initial **definition** asserted that the behavior of a person with mental illness requires that the caretaker place the needs and wishes of that person before his or her own. Within this broad definition parents who put their children's needs and wishes before their own would qualify as experiencing caregiver burden. Another difficulty with this sweeping definition is that it does not consider issues of guilt, stress, and stigma that are associated with caregiver burden. In

1991, moving from the broad to the specific, Parks and Pilisuk defined caregiver burden in terms of “more tangible and concrete (therefore measurable) aspects of care” (p. 502).

The concept of caregiver burden was further refined over time, but also complicated by the inclusion of multidimensional variables. Hoenig and Hamilton (1966) were first to distinguish between the **objective** (physical) and **subjective** (emotional) aspects of caregiver burden. Baines et al. (1997) use the word “caring” instead of burden: “Caring refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others” (p. 11). Parks and Pilisuk (1991) state that “objective burden” refers to the physical tasks and financial responsibilities of the caregiver, whereas “subjective burden” refers to subjective stress (e.g. when the caregiver confronts the meaning of the situation) and potential psychological costs (depression, resentment, anxiety, guilt) of being a caregiver. Further refinements were then made by other researchers such as Reinhard (1994), who asserts that objective burden comprises potentially different but observable variables such as financial strain, personal limitation in activities, and household disruption, and subjective burden consists of variables such as stigma, guilt, resentment, grief, and worry.

The notion of caregiver burden became yet more complicated as researchers introduced concepts related to multiple outcomes of the burden of the caregiver, such as well-being (Decker, Schultz & Wood, 1989; Stull, Kosloski, & Kercher, 1994; Young & Kahana, 1995), stress (Aranda & Knight, 1997; Dyson, 1992; Dyson, 1997; Chwalisz, 1982a; Chwalisz, 1982b; Chwalisz & Kisler, 1995; Frey, Greenberg, & Fewell, 1989), self-perception (Seybold, Fritz, & MacPhee, 1991), chronic sorrow (Phillips, 1991), and coping (Cathy, 2000; Cullen, MacLeod, Williams, & Williams, 1991). The first of these

studies that introduced Burden Interview (Zarit, Reever, & Bach-Peterson 1980) identified caregiver burden as a state resulting from the necessary care of an elderly or infirm person that threatens either the physical or mental well-being of the caregiver. Later, George & Gwyther (1986) and Maurin & Boyd (1990) broadened the concept of well-being to include further elements of the psychological health of a caregiver.

Western literature also evaluates caregiver burden in relation to professional and paid workers. For example, Jones and Jones (1994) explored the anxiety created in paid caregivers as a result of their work with disabled clients, including anxiety within the concept of caregiver burden. Similarly, a Canadian study focuses on the different forms of work done by women throughout their lives, within families as daughters, mothers, and wives in the context of individual relationships, and in the community as volunteers, as professionals such as social workers, nurses, and teachers, and as para-professional such as nurses aides and childcare and home health workers. The people who in such instances receive care are dependent because of disability or age (Baines et al., 1997).

Abel (1991) conceptualized the relationship between caregiver and care receiver as fluid and extremely complicated. She emphasized the need to always understand caregiver burden within the context of rich, long-standing familial relationships. This idea is particularly important when research takes a cross-cultural perspective, extending to, for example, any patriarchal society that emphasizes rich, long-standing familial relationships.

Caregiver burden experienced in the rearing of a child with a disability is associated with physical and emotional strain as well as financial burden (Crnic, Friedrich, & Greenberg, 1983; Frey et al., 1989). George and Gwyther (1986) assert that

caregiver burden includes compelling demands of a physical, emotional, and financial nature experienced by a person who provides care to a child with disability. Phillips (1991) suggests that chronic sorrow is not always present in mothers of chronically ill or disabled children. Seybold et al. (1991) found that mothers of children with severe disabilities were less satisfied with formal and informal supports and had fewer friends and family upon whom they could rely. However, Erickson and Upshur (1989) found that mothers of infants with motor impairments did not report difficulty in care-giving tasks, but did require more time to complete the same tasks than did a group with normal children. Significantly, mothers experienced different kinds of burden with different types of disabilities (Heller, Hsieh, & Rowitz, 1997).

The concept of caregiver burden has been examined in many studies in order to establish **gender differentiation**. A study by Parks and Pilisuk (1991) found that gender was an important variable in understanding differences in how the caregiver role was performed and experienced. Studies of gender differences clearly profile women as more frequently, intensively, and affectively involved in the caregiver role, a role that is associated with high psychological costs, inadequate support for effective coping, and deficiencies in respite care. Turner and Avison (1989) found evidence of higher levels of distress among females caregivers related to those receiving care. The women in this study were found to be more vulnerable to the psychological stresses of caring for significant others than were the men.

The conclusions of those studies focusing on gender converge around the issue of the role of the father and his perceived burden. Gallagher, Beckman, and Cross (1983) found significant differences in caregiving activities performed by fathers as against

those performed by mothers. In most families, fathers were found to be less involved in caregiving tasks than mothers. This study also found that where fathers of children with disabilities did become highly involved in childcare, they became involved only with boys. Conversely, Gallagher, Scharfman, and Bristol (1984) found no difference in the level of paternal involvement in childcare tasks whether the children had a disability or not.

The conceptual framework for the notion of caregiver burden in the literature is very obscure. Authors have defined caregiver burden inconsistently and with great variety. There are two plausible explanations of this opacity. First, authors perhaps did not personally know what caregiver burden was and made an attempt to define it according to their understanding. Second, the nature of caregiver burden is fluid, flexible across time and with different caregivers, which makes it very difficult for researchers to arrive at a consensus concerning the definition of caregiver burden.

Operational Framework and Caregiver Burden Scales. Although a great deal of research has attempted to **operationalize** the term “caregiver burden” with respect to those caring for chronically mentally ill adults, children with disabilities, and the frail elderly, many questions remain unanswered. Several unresolved methodological issues contribute to the confusion. Multiple operational definitions of caregiver burden have been developed, and these are specific to each study, and depend on the disability studied and the sampling of the study (Grad & Sainsbury, 1968; McAndrew, 1976; Zarit et al., 1980).

Researchers have developed a myriad of **caregiver burden scales** that can be divided into two types: unidimensional and multidimensional scales. It is clear that there

is no consensus in the literature about the dimensions that should be measured using quantitative instruments.

The **unidimensional** scales measure one holistic common aspect of burden. They focus on the caregiver's feelings and experiences, such as health status, financial strain, social activities and disturbed feelings. Although these scales support the idea that there are many aspects of a caregiver's life that may be affected by burden, they give only one total score and do not distinguish between different dimensions of burden (Novak & Guest, 1989).

Zarit et al. (1980) and Greene, Smith, Gardiner, and Timbury (1982) developed scales for caregivers of individuals with senile dementia that had 22 and 15 items respectively. However, Singhi et al. (1990) in their study combined three unidimensional scales: the Social Burden Scale (Pai and Kapoor, 1981), the PI Neuroticism Scale (Verma, 1978), and the Marital Adjustment Scale (Bhat and Gauba, 1978), a modified version of Locke's marital adjustment questionnaire (Locke and Wallace, 1956). A scale developed by Robins, Mace, and Lucas (1982) measures care burden using 52 items.

Multidimensional scales are those that consider many different dimensions of caregiver burden. These scales measure the patterns of association between various dimensions of burden. For example, the Caregiver Burden Inventory (CBI) measures five dimensions: time dependence, developmental, physical, social, and emotional burden. This scale provides a more comprehensive depiction of burden using a 24-item Likert-type scale (Caserta, Lund, & Wright, 1996). Subscales have a range from 0-20 and may have different numbers of items. The reliability coefficients for each of the subscales are

established, and multiple scores establish associations among different dimensions of burden.

Poulshock and Deimling (1984) and Montgomery, Gonyea, and Hooyman (1985) developed multidimensional scales that measure the care recipient's cognitive ability, average daily living (ADL) ability, impact on family relationships, and disruptive behavior by employing six and nine items, respectively. Lawton, Dleban, Moss, Rovine, and Glicksman (1989) measured emotional burden and the negative and positive qualities of the caregiver and care receiver relationship using a 47-item scale. The measures developed by Kinney and Stephen (1989), Novak and Guest (1989), and Vitaliano, Young and Russo (1991) are for Alzheimer's disease care providers and have 42, 24, and 25 items respectively.

The research studies contain a variety of operational frameworks and use an assortment of caregiver burden scales. All caregiver burden scales reviewed were designed for specific populations, such as those with senile dementia, the frail elderly, or patients who have undergone heart or hip surgery. The instruments were either used intact or in combination with another instrument or instruments, or were modified using material from other instruments with unidimensional and multidimensional aspects of caring. This lack of consistency raises issues regarding reliability and validity.

Methods of Sampling. To date, the caregiver burden literature contains three diverse sampling methods that include (1) diverse populations (2) different methods of obtaining samples and (3) paid versus voluntary samples. Cox and Monk (1993) examine Latino and Black caregivers in New York whereas Valle, Cook-Gait, and Tazbaz (1993) compare Latino and Anglo caregivers in San Diego, California. Both of these

comparative studies examined a diverse population of caregivers who cared for older adults affected by dementia. In a study by Chwalisz and Kisler (1995) participants were recruited from three different places: (1) at meetings of the Head Injury Association; (2) at a neuropsychologist's private practice in Iowa City, Iowa; and (3) from the Minneapolis Veterans Affairs Medical Center in Minnesota. Singhi et al. (1990) drew their sample from attendees of a pediatric outpatient clinic at the Postgraduate Institute of Medical Education and Research and the Rehabilitation Center for Handicapped Children, Chandigarh, India. Stull et al. (1994) recruited their participants by newspaper advertisements. The sample obtained by Walker, Martin, and Jones (1992) consisted of 141 mother-daughter pairs who responded to a newspaper article describing their project. These sample members were paid for participation in the study. One theme that consistently emerges in these studies is that participants were recruited by involving institutions.

It is evident from a review of the methodological dimensions of caregiver burden that there is variety and diversity in these dimensions. Most of the studies identified do not define the concept of caregiver burden explicitly, forcing one to make assumptions based on the variables under study. This lack of conceptual framework adds to the difficulty of operationalizing the concept, a process that involved different samples of caregivers for a variety of disabilities, diseases, and ages. The result has been the development of numerous widely divergent caregiver burden scales, some employing unidimensional and others multidimensional aspects of caregiver burden. Within the literature, there is no consensus on methodological dimensions because, first, the concept

of caregiver burden used was very fluid in nature and, second, burden was measured using a variety of samples and many different scales.

II. Paradigms

Caregiver burden is viewed through the lens of different paradigms. The two paradigms relevant to the current research are the postmodern and feminist approaches. A brief description of the paradigms will be presented in this section, followed by reference to qualitative research methodology.

Postmodern paradigm. A guiding tenet of postmodernism, according to Freedman and Combs (1996), is that “there are limits on the ability of human beings to measure and describe the universe in any precise, absolute, and universally applicable way” (p. 21). A process central to postmodernism is that of rigorously revealing and analyzing the assumptions, judgments, and values that underlie social arrangements and ideas.

Freedman and Combs (1996) defined the postmodern view of “reality,” worldview, as involving the following principles:

1. Realities are socially constructed.
2. Realities are constructed through language.
3. Realities are organized and maintained through narratives.
4. There is no essential truth. (p. 22)

Many interpretative studies of caregiver burden have used a postmodernist perspective. A common characteristic shared by both postmodern and interpretative paradigms is their ontological assumption that reality is complex, holistic, and contextual and that because “reality and human experience are variable, multiple ways of knowing are valued to uncover the knowledge that is embedded in human

experience” (Monti & Tinger, 1999, p. 71). Therefore, knowledge—implicit and explicit—is embedded in human experience and hence is tinted by the experiences and opinions of the generator of that knowledge.

Working from the postmodernist stance that reality is constructed and developed by those who experience it, it follows that people have an active role in creating and interpreting their constructed world (Clark & Standard, 1997). From this perspective, it has been suggested that caregiver perceptions are a key factor in degree and kind of caregiver burden (Chwalisz, 1982a; Chwalisz, 1982b; Chwalisz & Kisler, 1995).

Feminist Paradigm. The second paradigm that seemed useful in examining caregiver burden is a feminist perspective. Feminism focuses on individualism and equality of opportunity between men and women, although this philosophy is less a unified perspective than a collection of disparate approaches and focuses. Some overarching themes are a focus on women’s experience, as lived by women within their particular context, and including their feelings. Feminists believe that social roles should not be ascribed solely on the basis of sex. The outcome of research is to improve the lives of women and all persons (Lengermann & Niebrugge-Brantley, 1988).

There is tension between Western and Islamic feminists. According to Allen and Walker (1992) feminists incorporate voices previously unheard, which is one of the strengths that seems particularly relevant to the study of caregiver burden from the perspective of Pakistani women. However, Islamic feminists believe that one of the weaknesses of feminist theory is that it has focused mostly on the experiences and struggles of women in Western, industrialized societies. As a result, the

assumptions of feminist theory have generally been Eurocentric and ethnocentric in nature and have focused on the "presumed pathologies" of cultures, such as patriarchy (e.g., gender segregation, the veil, arranged marriages, clitoridectomies). Haj (1992) believes that patriarchy or cultural pathologies cannot be explained simply as a ubiquitous need of men to dominate women; an analysis of these phenomena must include other factors that rest on an understanding of cultural practices. In response, the feminist perspective is shifting in order to grasp these practices within their cultural and historical contexts.

Three assumptions of feminist research are relevant to the current ethnographic study. First, feminist research is grounded in women's experiences (Valentich, 1986). This assumption underwrites the current examination of the daily life experiences of women who care for children with disabilities. Furthermore, an interpretive research design based on women's experiences within their culture is the most suitable method of research (Olesen, 1994). Second, the differing status of informants and researcher is an important element of research (Valentich, 1986). The superior-inferior status differences between informants and researcher are a thread of the intersubjectivity that is co-created when differing experiences and contexts are brought together in an encounter between the researcher and participant. This approach is also comparable to ethnography (Olesen, 1992). Third, the objective of feminist research is to deepen one's understanding of one's context; it is, in effect, a design for social change (Valentich, 1986). This is particularly the focus of this research: to increase awareness regarding the cultural values and practices regarding Pakistani women and to call for social change.

Feminist scholars (e.g., Abel, 1991; Allen & Walker, 1992; Aronson, 1991; Nelson, 1990; Neysmith 1991; Neysmith & Aronson, 1993) have transformed experiential and critical analyses of caregiving as a form of women's work. Allen and Walker (1992) have focused on the positive and negative aspects of caregiving relationships between mothers and daughters. In her study, Rutman (1996) examines women's perceptions of "powerfulness and powerlessness" in working as caregivers. Neysmith (1991) and Neysmith and Aronson (1991) have focused on the caregiver population and are advocating for policy changes to provide better wages and services for paid and volunteer caregivers. Feminist and interpretive frameworks guided these studies (e.g., Abel, 1991; Allen & Walker, 1992; Rutman, 1996; Neysmith & Aronson, 1993), in which the researcher's own experiences as a caregiver provided the starting point and remained at the core of the inquiry.

In conclusion, the literature on caregiver burden converges on two tentative assumptions. First, most caregivers, regardless of the age, disability, or gender of the person needing care, are **women**. Second, there is a significant relationship between **burden** and **physical** and **emotional** outcomes.

III. Qualitative and Cross-Cultural Studies

Qualitative Research. The literature yields a few qualitative studies of caregiver burden using grounded theory, therapeutic utilization of a narrative paradigm, case study, and/or phenomenology methodologies. Several studies use qualitative methodologies with elderly populations. For example, Shyu et al. (1998) used grounded theory to explore the psychosocial process of family caregiving for frail elders in Taiwan. Walker

and Allen (1991) employed qualitative methods to obtain data on the nature of the relationship between elderly caregivers and care receivers. Rutman (1991) examines the enhancement of well-being of a caregiver; coping, role strain, and sense of oneself is explored by Shye and associates (1998); and Kurian assesses coping in families from a non-Western culture that is, in Jordan (1997). Although these studies consider different populations, they shared two similarities: the concept of caring and the use of interpretative methodologies.

The two qualitative studies that were most relevant to the current study were those of Vitalone-Raccaro (1993) and Glasscock (1997), who focused on caregivers of children with disabilities. These authors used a phenomenological methodology that examined the nature and expression of needs experienced by families of children with disabilities. Vitalone-Raccaro included 8 mothers of preschool children with disabilities, while Glasscock included 15 mothers of newborns with cerebral palsy. Their findings suggest that families of children with a disability need to (1) obtain community services, (2) explain the disability to other family members, (3) obtain family support, and (4) obtain information and professional support. These studies focused on the impact of caring for children who were very young, and suggest that caregiving becomes more difficult over time. While the sample set of these studies is similar to that of this study, they did not consider cultural and religious factors. Hence to gain an understanding of the cultural themes associated with caregiving, this research also scrutinizes cross-cultural studies in the literature.

Cross-Cultural Studies. The cross-culture studies of interest were from Jordan, Taiwan, China, Pakistan, and India. Studies indicate that Western culture has historically

viewed disabilities as a stigma (Levinson & Starling, 1981). Families with a disabled child were found to be reluctant to interact openly with others, and hence their social networks are small. This leads to family isolation, which in turn can add to the caregiving burden (McAndrew, 1976). In the Arab world, however, stigma is associated with getting psychiatric help (Al-Krenawi & Graham, 1999a). In Taiwan and India disability is kept secret in order to find suitors for the female siblings of a child with a disability (Shyu et al., 1998; Singhi et al. 1990). Two Indian studies (Singhi et al., 1990; Ilango & Nirmala, 1992) have reported on the adverse effects stigmatization has on the caregiver.

The Indian and Jordanian studies were selected for detailed review because of the similarities in culture and religion between those samples and the population of interest here. The study conducted by Singhi et al. (1990) studied psychosocial problems faced by Indian parents and other family members. Three groups were included: families with children with physical disabilities, families with children with mental disabilities, and families with healthy children (control group). A semi-structured questionnaire and standardized scales were used to explore variables such as financial stress, and poor social interaction. The findings indicated that the families of children with disabilities (both physical and mental) perceived greater financial stress, more frequent disruption of family routine and leisure, poorer social interaction, and more ill effects in general than did families of healthy children.

The Jordanian study (Kurian, 1997) of children with disabilities concluded that most of the burden of care usually falls on mothers, and sometimes on unmarried co-resident daughters. The idealized picture of extended family cooperation in caring for the handicapped seems to fall short of the reality as experienced by the women in this study.

The assumption that caregiver burden is shared by many members of the family, including the extended family, was contradicted by Kurian's findings. In Pakistan extended family is involved, but how the burden is shared is not well understood; however, one can assume, in light of women's restricted role in a patriarchal society that the burden would fall primarily on mothers.

Among all the studies mentioned above, Kurian's (1997) research is most relevant to this project because of significant similarities between the two studies and cultures. For example, he conducted the study in Jordan, which is an Islamic state similar to Pakistan. Second, both Jordan and Pakistan are non-Western cultures. Third, the scope of both studies is child disability, not gerontology. Finally, in both regions women are perceived, by Western standards, as oppressed. However, Kurian does not adopt a holistic perspective in his investigation; in fact, he maintains a comfortable distance from religious beliefs and values, which is not the intent within this research.

IV. Theoretical Framework

Two theoretical paradigms, ecological and role, have been utilized to explain or place disabilities and caregiving within a particular context. After a brief description of these paradigms, the rationale for the use of these theories in the current study will be discussed.

Ecological Theory. Ecological theory holds that individuals do not function in isolation, but in interaction with a variety of systems at different levels. It identifies three major systems within which people interact: the micro, mezzo, and macro systems. In addition, the theory assumes that people are constantly adapting to

their environment and that they must be viewed in the context of the environmental systems that surround them (Queralt, 1996; Ward, 1998). When ecological theory is applied to the issue of caregiving for children with disabilities, attention is focused on understanding disabilities and caregiving in the context of an individual in interaction with a number of systems.

Ecological theory is of benefit in the attempt to understand, in the context of their social systems, mothers who provide care to a disabled child. This study sees the interaction between the mother and the child with a disability and other family members as occurring on a micro level, interaction with extended family and neighbors as on a mezzo level and interaction with social, cultural and religious beliefs and values as on a macro level. This view contrasts with that prevalent in the West, where there is provision of formal services (mezzo level) and governmental and agency policy (macro level). Nonetheless, all three level of interaction are considered when one adopts an ecological framework.

Another important element in ecological theory is its focus on a broader system for understanding human problems and the intervention process. **Change** can occur at any level and affects the other levels. The real strength of ecological theory is in its explanation of how individuals and systems interact and contribute to both the individual's problems and the solutions to those problems (Ward, 1998). This suggests that mothers who care for children with disabilities are involved with many different levels of systems that can both benefit and hinder them in their roles and responsibilities as caregivers. This brings us to the next topic of interest: role theory.

Role Theory. The second theoretical paradigm that can provide a framework for this study is role theory. The concept of **role** refers to the characteristic behaviors performed by a person holding a certain social position. Roles are classifications of behavior. Societal values define roles, and all roles have limitations imposed by these values. Roles do not exist in isolation, but rather are designed to fit within a social structure in which every individual holds a **position or status**. **Position** refers to the set of rights and obligations that regulate one's transactions with other individuals, of the same or differing status. **Status** refers to the relative social value of the position. For example, a mother's position and status, as determined by the culture, entails certain rights (e.g., respect, love, and obedience) and certain obligations (e.g., caring, nurturing, support). In order to maintain position and status, mothers are obligated to fulfill these expectations and obligations.

Role theory centers on the view that individuals play many parts in their lives, the basic scripts for which were developed by others yet whose enactment is unique to that person. This suggests that although a motherhood script is culturally developed, every woman fulfills this role in a unique fashion. Roles maintain social structures. The stability of a social structure depends in part on the extent to which individuals comply in the expected role behaviour; this mechanism assures conformity to socially normative behaviours, and thus stability. This prescribed role behaviour, derived from an emphasis on position and status, in turn reinforces the stability of the system (Davis, 1996).

Generally, there is a high level of agreement on what the role expectations are for a mother or caregiver, expectations that include both rights and obligations.

Thus, a mother's role identity is the sense of self that is derived from the positions she occupies and the adequacy with which she and significant others judge that she performs her role. This evaluation of role performance transforms into **role identity**. Self-understanding is developed through repeated performance and reciprocal interactions with others, and this process helps internalize our social identity (Davis, 1996; Stearn, 1979).

The literature does not provide any study that emphasizes the role of women as caregivers in a positive manner. A child with disability is dependent on the caregiver for social, emotional, and physical needs that were related to negative outcomes in caregivers extensively cited in every definition of caregiver burden. The literature addresses the idea of self-concept, but only in relation to social support (Blankfeld & Holahan, 1999; Erickson & Upshur, 1989; Seybold et al., 1991); the concept of shaping caregive role-identity from positive outcomes is absent.

2 PAKISTANI LITERATURE

Two aspects of the Pakistani literature are reviewed: contextual factors and social values. This section first presents some of the problems related to a literature review and then identifies some concepts from special education research that are relevant to the current study. The practical framework demystifies the local situation in Pakistan and the theoretical framework sets the stage for the current study.

Two problems beset this review of the Pakistani literature: the absence of the concept of caregiver burden and the difficulty of accessing Pakistani literature from the West. Most of the information available provided statistical data on women's education, health status, and disabilities. Most studies focused on issues relating to

health, education, and economics, simply because of the immense nature of these problems (Adeel & Naqvi, 1997; PARD, 1994; Tinker, 1998). There are two possible reasons why it is difficult to find studies on caregivers in the Pakistani literature. First, in Pakistan social issues such as honor killing, child sexual abuse, domestic violence, HIV, and drug addiction have only recently been recognized. Perhaps this new awareness is the work of NGOs. To date, however, researchers have focused on etiology rather than prevention or health promotion services. Second, new problems are usually tackled by interventions and research on the primary population; only later do these trickle down to affected invisible populations such as service delivery professionals and populations far removed from funding and policy. For example, in the area of disabilities in Pakistan, the primary population is the children; the secondary is professionals and para-professionals and then the families in general and the caregiver in particular. Invisible populations such as caregivers are recognized only when they demand services, although they put a great deal of work into caring for those with disabilities.

The contextual framework for this work is based on health, education, economic, and disabilities literature available in Pakistan, although there is currently no research on the concept of caring of any kind. The social framework provides an understanding of the religious and sociocultural value systems of Pakistani women and caregivers.

I. Contextual Framework

Studies in England (Beresford, 1994; Shearn and Todd, 1997), the United States (Caserta et al., 1996; Chwalisz, 1982a; Chwalisz, 1982b; Chwalisz, & Kisler,

1995; Crmic et al., 1983; Dunst, Trivette & Cross, 1986; McAndrew, 1976; Stull et al., 1994), Jordan (Kurian, 1997), China (many studies were in the Chinese language and were cited in Shyu et al., 1998), and Taiwan (Shyu et al., 1998) indicate that caregivers worldwide are typically women.

Health Status. The population of Pakistan is probably unique in the world in having fewer women than men. According to the World Bank, in Pakistan there are 91 women for every 100 men, compared to a world average of 111 women to every 100 men. Among 15- to 40-year-old women (this segment comprises most mothers and caregivers of children with disabilities) there are 75% more deaths than among men of the same age range (cited in Tinker, 1998). This greater mortality is attributed to nutritional anemia and the attendant health problems resulting from discrimination against women in the obtaining and sharing of food. For example, the World Bank reports that 45% of women suffer from iron-deficiency anemia during pregnancy and lactation (Filmer, King, & Pritchett, 1998; Pakistan-country gender profile, 1998). Pregnant women on average consume only 89% of the recommended protein intake, and 29% of pregnant women consume less than 70% of the recommended protein intake.

Additionally, it is well documented (National Nutrition Survey of 1985-87, 1988) that pregnancy and lactation require an increase in caloric consumption. However, of the recommended intake for pregnancy and lactation, Pakistani women only get 87% and 74% calories, respectively: 28% of pregnant women and 46% of lactating mothers consumed less than 70% of the recommended calorie intake. The

result is a loss of weight and reduction in overall health known as “Maternal Depletion Syndrome” (Papanek, 1990; UNICEF, 1992).

Women with maternal depletion syndrome have decreased immune function, and repeated pregnancies make them highly susceptible to fatal diseases. According to the World Bank, only 5% of births were institutional deliveries, as a result of customs regarding the segregation of women coupled with their reluctance to be treated by male health professionals and a dearth of female medical professionals (Tinker, 1998). Only 30% of the population had access to sanitation in 1995: in the same year only 60% of the population had access to safe water. In 1995 public expenditure on health in Pakistan was 0.8% of the Gross National Product (GNP). All these factors are significant predictors for giving birth to a child with disability, according to the World Bank (1998), which lists among the causes of disability malnutrition of mothers and children, prenatal or perinatal damage, infectious diseases (including ear and eye infections), and environmental factors (Papanek, 1990; Tinker, 1998).

Educational Status. In Pakistan the socially prescribed role of women is limited to raising a family; education is not considered a priority for girls. As in other matters of daily living, a male child is given preference, due to the limited availability of educational resources. The result is that the literacy rate for women in Pakistan is 16%, one of the lowest in the world. After the primary school level the dropout rate of women accelerates, and only 0.8% of women achieve a university education (Mumtaz & Shaheed, 1987). Overall, only 2% of Pakistan’s GNP was spent on education in 1980 (Selected World Development Indicators, 1991).

Work Status. According to the International Labor Organization (ILO) report to the World Bank, only 13% of Pakistani women were wage earners. However, the fact is that almost all Pakistani women work. For example, rural women work, on average, a 14-16 hour day and assume all responsibility for food preparation, cleanliness, and the general welfare of the family. They also collect fuel and fodder, make and repair their primitive mud stoves, repair the mud walls of their homes, and look after any domestic animals their family may own (Tinker, 1998).

In the urban centers, it is estimated that 24% of the female population is engaged in the service sector as sweepers, cleaners, dishwashers, cooks, and maids in private homes, hospitals, schools, hostels, and hotels. Overall, there is an increasing number of women employed in factories--notably textiles, pharmaceutical, packaging and fisheries (Mumtaz & Shaheed, 1987). However, neither private nor public industries in Pakistan address the personal needs of workers regarding child-care or respite services.

Disabilities. Disabilities in Pakistan, both physical and mental, appear to be widespread and under-reported. For example, a survey of two million people in the Islamabad and Rawalpindi districts found a 2.6% prevalence of disability in the population, although some estimates derived from other micro-studies greatly exceed this figure (Ministry of Health, 1987). This survey also categorized disabilities by type and by age group. It reported that, 21% of Pakistanis had mental disabilities, 15% visual, 9% hearing, 21% multiple, and 33% physical disabilities. With respect to age groups, 12% of those aged 0-4 had a disability, 16% of those aged 5-9, 15% of those 10-15, and 57% of

those over 14. Children under age 14 made up 43% of the disabled, with most of them (33%) having a physical disability.

Table 3.1 Moderate and Severe Disabilities in Children Aged 2-9 in Karachi

Disability	Boys	Girls	Total Average
Mental Retardation	18.91	19.12	18.99
Motor Impairments	18.91	20.27	19.53
Vision Impairments	20.74	8.47	15.09
Hearing Impairments	8.65	1.15	5.17
Seizures	5.06	5.00	5.04

Directorate of Special Education, 1991

Prevalence /1000

Table 3.1 shows the result of a recent micro-study in Karachi of children aged two to nine that found a 57.7% rate of impairment (which can include very minor conditions), and a 20.9% rate of disability, with 2.95 % having moderate disabilities. In general, rural rates were double urban rates, with the exception of motor disabilities, which were over three times more common in rural areas (UNICEF, 1989).

Another study (UNESCO, 1990) indicates higher rates of severe disability, in all categories, among boys. However, mild disability does not have as adverse an effect in rural and agrarian communities, where the emphasis on education is low, collective and cooperative living is a general rule, and many mildly retarded children fulfill the social functions expected of them (Miles, 1991).

Given the typical division of labor within the family, in Pakistan it is the mother who cares for a child with disability. The findings were similar in the Western, Arab, and Chinese literature, where women, as a relative or as a professional, were over-represented in the caregiver samples (Chwalisz, 1982a; Chwalisz, 1982b; Chwalisz & Kisler, 1995; Caserta et al. 1996; Crmic et al. 1983; Dunst et al., 1986; Novak & Guest, 1989). How mothers perceive their work of

caring, for children with disabilities has not been conceptualized or systematically studied in Pakistan. However, a range of opinions and feelings has been recorded. Most common are feelings of powerlessness and ignorance, compounded by shame at what is considered a divine punishment (Mumtaz & Shaheed, 1987). This feeling is sometimes given concrete expression in the form of total seclusion and extreme neglect of a child with a disability. Lack of understanding of disabilities, exacerbated by misinformation from relatives and health workers, can result in uninformed choices that may contribute to lifelong disabilities (UNICEF, 1992).

Other studies give a different impression of children with disabilities. For example, the people of Pakistan believe that a disability is a condition to be accepted with fortitude; to reject it would be to rebel against Allah's will (Miles, 1995). This stoic attitude is found among poor and uneducated people as well as educated and resourceful people. Another, similar belief is that if effective intervention can be undertaken, it should be done with Allah's blessing (Miles, 1988, 1991, 1995).

Miles (1995) has traced historical notes on disabilities in East Asian writings spanning over 2,500 years. Safeguards pertaining to the disabled appear in legal codes in the Indian subcontinent, probably originated in the second century B.C., and can be found in sources. It was the practice then, as now, to send mildly retarded children to regular schools where they received integrated education (Miles, 1988). Miles' research, however, does not address the concept of caregiver burden. One reason for this omission could be that Miles' interest was limited to issues in special education of children with disabilities.

II. Social Framework

Because caregiver burden is not an idea that has been recognized in Pakistan, the scope of the problem is unknown. However, by looking at the incidence of disabilities and at women's status in Pakistan, one can draw some conclusions about the societal values regarding caregiver burden.

In Pakistan, the military dictatorship of Zia-ul-Haq, which lasted from 1977 to 1988, established and enforced a series of measures founded on a fundamentalist interpretation of Islam that limited the legal rights of women as well as their educational and employment opportunities. Women were confined to “chardar and char dawari”—a veil and four walls. This decade of dictatorship is considered to have surpassed any in history in the degradation of Pakistani women (Alavi, 1997). Zia-ul-Haq effectively used religious notions to make political gains, creating what Lateef (1998) refers to as political religion. Hijab (1998) also identified this shift, denouncing the use of Islam as a weapon against Muslim women. Some Arab (Ahmed, 1992; El-Saadawi, 1997; Mernissi, 1996; Wadud, 1999) Pakistani (Hassan, 2001; Shaheed, 1995), Bangladeshi, (Hashmi, 2000) and other (Esposito, 1998; Stowasser, 1998; White, 1978) scholars are challenging fundamentalist interpretations of Islamic values for women, advocating equitable status of women and men. The following sections will present and discuss the religious belief systems and sociocultural practices that lay the foundation of Pakistani society.

Religious Perspective. Historically, before the advent of Islam, the Arabs treated daughters as sources of shame and often practiced female infanticide. Some Islamic scholars support the subordination of women and consider Islam to be the

symbol of excellence in this area (Azeem, 1995). However, the Koran severely condemns these practices:

When the birth of a girl is announced to one of them, his face grows dark and he is filled with inward gloom. Because of the bad news he hides himself from men: should he keep her with disgrace or bury her under the dust? How ill they judge! Evil are the ways of those who deny the life to come (Dawood, 1974, 16:59, p. 308)

When the infant girl buried alive is asked for what crime she was slain; (Dawood, 1974, 81:7, p.17).

It is ironic that Muslim women suffer some of the greatest inequities on the globe, given that Mohammed, the prophet of Islam, was among the world's greatest reformers on behalf of women. He abolished such sex-discrimination practices as female infanticide, slavery, and levirate (marriage between a man and his brother's widow), and introduced the idea of women having a guaranteed right to inherit and bequeath property and to exercise full possession and control of their own wealth (Hashmi, 2000; Khan, 1990; Rouf, 1977). Islam, in fact, may be the only religion that formally specified women's rights and sought ways to protect them. Today's Islamic spokesmen from all over the Muslim world frequently extol the Prophet's revolutionary innovations, but usually fail to note that they are rarely honored in practice (Goodwin, 1994).

There are some changes taking place in Muslim countries, and women are becoming increasingly aware of and involving themselves in changing their subordinate situation. An Arab female Muslim scholar, Mernissi (1987, p xiii), in a very powerful introduction to her book Beyond the Veil, disagrees with perceptions of Muslim women as being subjugated to religious beliefs. She asserts that "Muslim

women, illiterate and educated alike, were coming to diagnose and verbalize their problems—previously identified and labeled as being emotional—as being essentially political.” Women believe that it is contradictory to the teaching of the Koran that they receive unequal treatment. The whole notion that a just God requires the social injustice that currently exists in Pakistan is coming into question (Ahmed, 1992; Mernissi, 1991; Lateef 1998; Shahid, 1995).

Some Islamic authors, in an attempt to understand gender roles in Islam, have gone to great lengths to interpret the Koran and Traditions (teachings and sayings of the prophet Mohammed) from the historical and contextual points of view (Ahmed, 1992; Sonbol, 1996; Hashmi, 2000; Hussain, 2001; Mernissi, 1991; Wadud, 1999). Mernissi (1991), and Wadud (1999) offer an interpretation of the text from a woman’s perspective. These authors believe that a revolutionary process is taking place in the Muslim world, that it is not talked about much but will change women’s status with Islam’s blessing. They believe this change is inevitable, but will, however, occur only very gradually.

Few issues in Islamic and Muslim cultures have attracted more interest than those involving the treatment of women. For many non-Muslims, the topic of women evokes images of deserts and harems, *chador* and *hijab* segregation and subordination. There is a perception in the West that Muslim women are subjugated and second class. But there is no one monolithic Islamic view of women. There are, within Islam, diverse interpretations of equality for women. The sheer range of views has been profoundly affected by two factors: Islamic beliefs that are influenced by diverse local cultures, and the primary role of men rather than women in interpreting

Islamic law and traditions (Haddad & Esposito, 1998). Additionally, given that many non-Islamic countries have such problems as high female illiteracy, it is well to bear in mind that gender inequality in Pakistan may be more reflective of its patriarchal social structure than of Islamic teachings.

It is relevant that from a religious standpoint, women's social position is secured by performing service. According to Islamic belief, an *ihsan*, refers to a service to another and the person who renders such a service is considered "special" to Allah. The concept of *ihsan* effectively secures the role of mothers of children with disabilities and provides them with additional importance. In this way, the Islamic religion grants some recognition, reward, and gratification to women who care for a child with disability.

A study by Miles (1990) focusing on Islamic teachings indicates that there are provisions in Islamic law for the disabled, such as security and welfare of the person and his/her property. The Koranic text prescribes guardianship for persons with mentally disabilities. For example, a "light-minded person" or *safiyah* (in Arabic) is defined as a little child because his or her mental deficiency requires that that person be protected and taken care of. Indeed, an individual with a disability is considered to be "holy" or "lucky," and people around the *safiyah* are obliged to care and provide for him or her.

In conclusion from a religious perspective very little attention has been paid to Islam in the literature on social work practice. Studies focus on Islamic social transformation (Haynes, Eweisi, Mageed, & Chung, 1997) and spiritual diversity in social work practice (Canda & Ferman, 1999). Al-Krenawi (1996) and Al-Krenawi

and Graham (1996, 1999, 2000) focus on the significance of social work practice on Arab Muslim healers. An Indian study on the concept of *mahr* (dowry) borrows extensively from the Islamic text and outlines steps to ensure better working of the *mahr* from the social work perspective (Wani, 1996). Although in the mental health field there are many studies taking Islam into consideration, such as psychotherapy in Islamic societies (Al-Abdul-Jabbar & Al-Issa, 2000), family therapy in Muslim families (Carolan, Bagherinia, Juhari, Himelright, & Mouton-Sanders, 2000; Daneshpour, 1998), and Koranic healing (Al-Krenawi & Graham, 2000), there is to date no research on the role of a caregiver or caring within the Islamic context.

Sociocultural Perspective. In Pakistan, the sociocultural perception of women, in general, is that they should be subservient. A female child is not welcomed or valued as compared to a male child and there is still significant shame attached to the birth of a female child. A woman who gives birth to a girl may be blamed, tormented, and ridiculed, and is seen as having total responsibility for the child's sex. This belief persists due to poor education and a strong value system that does not understand (or prefers to remain oblivious to) the genetics of reproduction (i.e., that males determine sex by passing or not passing on a y chromosome). Such denial is a cultural and societal safeguard to protect men's social status (Mumtaz & Shaheed, 1987).

In a patriarchally organized society, role gives status that provides power within social relationships between men and women. Socially, Kandiyoti (1988) has illustrated that different male dominance patterns provide very different contexts within which women contest, accommodate, and negotiate their relationships with men. These contexts are fluid and readily changed by historical developments, which

open up new grounds for conflict and resolution in the relationship between the genders. Women have various roles in a society, but the most recognized roles are those that are directly associated with men. Being a wife, mother, daughter, or sister may elevate a woman's status in her society (Mernissi, 1987). In other words, interpersonal relationships are a resource. For example, women gain recognition and status when they are related to a man who has a high position or financial status.

The daily reality of Pakistani women is not different from that of women of any developing country, where most women perform vital and extensive labor. The issue is not one of limited resources, because the Arab world, with its limitless petro-dollars, has high illiteracy rates among its female population. For example, according to UNESCO (1990), 75% of Saudi Arabian women are illiterate, one third of Moroccan women and one half of Algerian, Egyptian, and Libyan women; and 80% of Sudanese, Somalian, and Mauritanian women are without much education. The irony of the Pakistani woman is that she is denied education more as a result of societal values than of limited resources.

Chapter 3

RESEARCH METHOD

This chapter presents the ethnographic method and the rationale for choosing this approach to this study. Also discussed are issues central to this research, such as the recruitment of participants, data collection and analysis methods, ethical considerations, and the trustworthiness of data. The data collection techniques include interviews, participant observations, document reviews, and visual ethnography. The data analysis techniques chosen include description, analysis and interpretation (Wolcott, 1994). The research was conducted within the author's own culture of origin, and therefore, this chapter includes a section on subjectivity with respect to culture that presents some of the advantages and dangers of doing such research. Finally, issues related to translation are presented.

Qualitative research is a field of inquiry that cuts across disciplines, fields, and subject matter. Qualitative researchers draw upon and utilize the approaches, methods, and techniques of ethnomethodology, phenomenology, hermeneutics, feminism, rhizomatics, deconstructionism, ethnographies, interviews, psychoanalysis, cultural studies, survey research, and participant observation to arrive at important insights and knowledge (Nelson, Treichler, & Grossberg, 1992). Denzin and Lincoln (1994) describe it in these words,

Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of meanings people bring to them" (p. 2).

“Ethnography is the work of describing a culture...from the native point of view,” according to Spradley (1979, 3). Bronislaw Masinowski, a British anthropologist who is generally viewed as the inventor of intensive cultural fieldwork, describes in his book Argonauts of the Western Pacific (1922) the purpose of ethnography as “to grasp the native’s point of view, his relation to life, to realize his vision of his world” (1922, cited in Roper & Shapira, 2000, p. 1). Roper and Shapira point out that “ethnography is a research process of learning about people by learning from them” (2000, p. 1).

Agar (1996) believes that when a culture is “unknown it should be learned...[it] has a pattern that must be discovered and interrelated with other patterns” (p. 243). Care behaviors are patterns that can be distinguished in every culture, although there are some similarities and differences that relate to specific cultural patterns. The discovery and comparison of these cultural patterns makes ethnographic research educative and adds to the existing knowledge base. Caregiving behaviors in Pakistan for example, are unknown, and must be identified. To accomplish this the first requirement is to conduct a “factor-searching inquiry” that answers the question, “What is this?” The answer to this “descriptive, relation-searching” investigation offers a second order of inquiry that answers the question, “What happened here?” (Munhall & Oiler, 1986, p. 147).

Ethnographic researchers seek to learn from those being studied and to understand their perspectives, customs, behaviors, and meanings within the context of their culture. In doing this, the researcher tries to “lose her own baggage.” It is imperative that the researcher defers his or her judgments, preconceived stereotypes,

and interpretations of behaviors that arise from the researcher's own experience and culture. Through suspending one's "worldview," one can gain insight into patterns of interest, such as cultural values, family structure, religious practices, child rearing, conventions, experience of daily life, concept of poverty, and self-perceptions (Locke, 1992).

Conceptually, culture is divided into two fundamental components: behavioral and cognitive (Fetterman, 1989; Spradley & McCurdy, 1972). The behavioral component of research investigates patterns of behaviors, customs, work, and ways of life (Harris, 1968). The cognitive component is what makes sense of the ideas, beliefs, and knowledge that guide subjects in living their lives. Ethnography is based on the notion that culturally based value systems influence behavior. To achieve cultural competence, it is imperative to learn and understand the attitudes and values of the group being studied. When dealing with a diverse culture especially, there is always a threat of developing stereotypic views and assumptions that are damaging to both culture and scholarship. In this sense, one gains a great advantage in studying one's own culture. Such research provides the researcher with an opportunity to understand the multiple complexities of a culture, to which the researcher is highly sensitive because of his or her membership in the culture.

There are three fundamental characteristics of ethnography: researcher as an instrument, place, and recurring nature of data collection and analysis. To become an instrument of research requires the researcher to immerse him or herself in the culture for a length of time. In this way, the researcher becomes an instrument that gathers, describes, analyzes, and interprets data. Thus ethnographic research places

essential emphasis on fieldwork. The researcher is required to take on a dual role, maintaining an outsider's view while gaining an insider's perspective. This dual role is referred to in several ways in the literature, as, for example, the emic and etic views, cross-dresser, or subjectivity and objectivity. When a researcher fails to maintain objectivity by getting enmeshed in the experience, he or she is considered to have "gone native" and the research may no longer be valid. By maintaining an outsider's view, the researcher interprets information about patterns and relationships using his or her own frame of reference (Streubert & Carpenter 1995).

The second characteristic of ethnography is place. A researcher must go physically to a place for a certain period of time to observe and gather data (Streubert & Carpenter, 1995). This allows the researcher to experience the day-to-day life circumstances of the study population, which provides excellent insights into those circumstances. Thus fieldwork, as noted above, is an important technique of this method.

The third characteristic of ethnographic research is the recurring nature of data collection and analysis (Streubert & Carpenter, 1995). The landscape of human life is rich, dynamic, and wide-ranging. Agar (1986) asserts that there are no clear boundaries of similarities and differences in human experience. Because societies are complex and dynamic in nature, there are always questions left unanswered in the process of learning, and therefore the recurring nature of data collection and analysis is imperative to this method. This feature makes the method attractive because it always involves the pursuit of knowledge in shared experiences.

There are two types of ethnographies: micro (also called mini) and macro (also called broad). Micro ethnography is a smaller research project with few subjects and requires less time in the field (Germain, 1996; Leininger, 1985). Micro studies have a narrow or specific focus, such as Miller's study (1991) of six people over a period of six weeks. Conversely, a macro study "looks at the culture in a broader context, extends over a larger period and is most often reported in book form" (cited in Streubert & Carpenter 1995). However, Wolcott (1985) rejects this notion completely stating that "time alone provides no guarantee that one has come to know or understand a setting thoroughly." He thinks that acquisition of knowledge depends on the "researcher's skill, sensitivity, problem and setting" (p. 189).

Caregiver burden as we have seen, is not a concept recognized in Pakistani literature. The use of sophisticated unidimensional or multidimensional scales in this study did not appear to be feasible for several reasons. First, the literacy level in Pakistan is very low, and if these scales were translated into Urdu (Pakistan's national language) too much of the meaning implicit in them could be unclear to Pakistani mothers. The second difficulty is that to discuss burden in an impersonal way is in the Pakistani culture, to betray God (Miles, 1995). Third, people in general and women in particular are not used to surveys or questionnaires and would not be willing to participate in such research. Finally, there is a great deal of skepticism about Western concepts and ways. Caregiver burden is considered a Western concept, and to measure it with Western-derived scales, surveys or questionnaires would be regarded as impersonal, oversimplified, and superficial, as well as failing

to capture culturally embedded information. Ethnography then, seems the most appropriate research method.

There are a number of reasons for selecting ethnography as the method for the current research, among them: (1) to learn alternative realities, (2) to discover new theories grounded in context, (3) to understand a complex society, and (4) to understand human behavior (Spradley, 1979). Pakistan has many intricate religious and sociocultural meanings, beliefs, and customs and cultural realities. Leininger (1991) points out that care behaviors are different in different cultures because of the variations in social structure, worldview, and the cultural values of the people. Thus although term “caregiver” may have a similar denotation in both Western and Pakistani cultures, it may have different connotations because of different religious, social, and cultural frameworks. The structure of ethnography includes an analysis of cultural themes that will aid in understanding the meanings of the practices of the particular society of concern.

To summarize, the process of ethnography is to access a setting and population (a part of culture), and to uncover the themes. Then the relationships among the themes are considered, and finally, these relationships are examined in relation to cultural context. This process produces a descriptive or explanatory theory. To identify these patterns, one must enter the culture without a hypothesis about what will be discovered and gain insight through participant observation, interviews and supplementary data sources—in short, as we have noted, the researcher is expected to immerse him or herself in the culture.

This following section will discuss the recruitment of participants and the data collection methods used in this study. Four methods of data collection will be described: participant observation, interviews, analysis of official documents, and visual ethnography.

Recruitment of Participants

Key informants were recruited before the research project started. The first key informant is the former principal of a school I had contacted before choosing the subject for this research. After I explained my research interest, she agreed to get me entry into the special education system. She has a master's degree in special education from the United States and has been working in the area of special education since the 1980s. When I returned to Pakistan in 1999 to gather data, this individual had been transferred to the teacher training division. However, she is familiar with the special education system, the population of interest, and had provided direct services to children with disabilities.

The second key informant is a professional teacher who had married into an agriculturalist family who live in a small village. She, her two teenaged children and her husband lived in Islamabad and lead a relatively Western lifestyle in that her children are being educated in British private schools. Her husband is the patriarchal head of the family, who makes frequent visits to the village at the time of the harvest or to obtain goods or services required by the family. This family typically spends their vacations and summer holidays in their village. The family lives together in a big house divided into small units to provide space for the use of members of the extended family. Within the house, genders are segregated: there is an outer house

for men and an inner house for women. The women rarely go outside, and when they do they observe strict *pardah* (veil). Only men who are family members come to the inside house (where the older generation lives and where genders can mix albeit with modesty). This informant was chosen because she has strong links to her village and her extended family, as do most of those who participated in this study.

Sample Selection: The sample used in this study included eleven mothers who provide care to either one or three children with disabilities. All eleven are of low to low-middle socioeconomic status in Pakistan. All of the children from these families attended government special education schools. The government of Pakistan funds these schools, and only those parents who cannot afford to send their children to private schools or to hire a full-time servant/caregiver tend to enroll their children in these schools. These mothers lived in various regions of Islamabad and communicated in Urdu, Punjabi (the provincial language), or one of the dialects of Punjabi. They represented different regions of Pakistan (mostly from Punjab, two from Sindh, and two who immigrated from India at independence and spoke Urdu). This diversity increases the study's applicability. It is a convenience sample of willing mothers and family members who agreed to share information about their culture and experiences.

The literature links the severity of a disability and the age of the child to the degree of caregiver burden (Lefley, 1987; Phillips, 1991). Miles (1989) reports that in the 1981 National Census disabilities were classified only into the categories of blind, deaf and dumb, crippled, mentally retarded, insane, and others. The participants in this study were selected on the basis of the child's disability type—

that is, mental retardation—rather than severity. The sample included caregivers of children with mental disabilities who attended government schools. I observed that these schools did not have students with severe mental disabilities, or physical or visual disabilities. However, the schools kept no professional records or documentation on the severity of mental retardation or the types of disabilities. The classification of disabilities is very loose and lacks diagnostic criteria by Western standards.

Gaining Access: I approached the Directorate of Special Education (DSE) in Islamabad upon my arrival in 1999. One of my cousin's in-laws, Malik Mukthar, is a director of the DSE. He introduced me to the acting principal of Fatima Jinnah School and director of DSE, Izhar Hussain. A copy of the proposal was provided to Mr. Hussain and Ishart Masud, principal of Ibna-I-Sana School. Attached to the proposal was a letter from Dr. Margaret Williams, University of Calgary, verifying my status as a student researcher. As well, Mr. Mukthar had requested cooperation from school staff, thus paving the way for my entry. I spent all my time at the schools simply observing the system, learning about the dynamics at work in the schools, developing an understanding of the hierarchy, developing rapport with the school staff, and getting to know the children.

During my time at Fatima Jinnah School, I approached one of the teachers who acted as a deputy and who was well informed about all the students and their parents. I asked her to give me the names of children whose parents might be comfortable with my asking them questions and visiting their houses. She provided me with twelve names. In Ibna-i-Sana I visited every class and asked the class

teachers to provide me with at least one name of a parent whom they felt could be approached. Most teachers provided several names: the list was taken to Mrs. Masud, who narrowed it to twelve parents.

Data Collection Methods

Data were collected by unstructured interviews over a period of two months. Except for the two interviews that took place in the school, all interviews took place at the mothers' homes. After about a year, member check interviews took place at the Shifa Falahee Clinic, where I was employed and where some of the mothers came for medical care.

Participants interviewed did not work outside the home, except for one who worked at a hospital as an *ayia* (nurse's aide). Interviews, all of which were taped, ran for various lengths of time, depending on the information being given. All participants except one were interviewed at least twice at the school or home, in order to obtain an in-depth understanding of the cultural norms, customs, and values of Pakistan. As well, short conversations focused on the research questions were recorded with other family members who were present at the time of home visits.

Only open-ended questions were used in obtaining demographic information from the participants. In unstructured interviews the participants had the opportunity in as many words as they needed, to describe an event or their feelings. This method of interview broadened the focus and opened up for discussion participants' conceptual frame of the issue of caring.

Interview Framework In this section four methods of data collection will be discussed: interviews, participant observation, document reviews, and visual ethnography.

The interviews conducted focused on the primary open-ended question:

What are the daily life experiences of mothers who have children with disabilities? According to Fetterman (1989), “the most important question to avoid is the stand-alone vague question” (p. 54). However, at times I asked questions in order to develop rapport as well as a better understanding of the themes. I, of course, share the ethnic background of the subjects, which Best and Kahn (1998) believe is important in an interview: interviewers of the same ethnic origin as their subjects seem to be more successful in establishing rapport, and those of a different ethnic group may encounter a certain amount of suspicion and even resentment.

Participants seemed comfortable in asking me questions to clarify my purposes and to gain knowledge of my personal life and experiences. A few times they treated me as an expert and wanted me to advise them in decision-making regarding their child. I avoided making recommendations and instead asked them to consider what they needed to learn before they could make an informed decision.

Data were generated by tape-recorded interviews, participant observations, and analysis of documents and photographic images. A framework for data gathering was used with the following guidelines:

- Recognition that each mother is a person and not just a source of data.
- Maintaining dialogue with the mothers on an equal level regardless of professional or social status in the process of creating human inter-subjectivity.

- Listening with my total being in order to understand the experiences of these mothers.
- Reviewing my own beliefs before and after each interview using the technique called “bracketing” (attempting to put aside my own knowledge, preconceptions, and values to understand what it is like to be the mother of a child with disability).

Interview Process. Most of the first interviews were held in the homes of the mothers, except for two informants, who, as mentioned, came to see me at school the day after they received the consent form. Interviews were semi-structured to allow each mother to tell her story in her own way. As sound interviewing techniques enhance the quality of information gathered from an interviewee (Fetterman, 1989), acting naturally and being oneself is better than any planned performance or strategy. Having interviewed hundreds of families and individuals in clinical settings, I see the value of unstructured interviews; however, the objective is always clear and achievable during the process. The primary and most essential objective is to build rapport with the interviewee. Only when rapport was established did the focus shift into the question of the inquiry and the data provided by the interviewee.

I reviewed the tapes of the first interview in preparation for the second interviews. These interviews ranged from 20 to 60 minutes. All were conducted in a relaxed atmosphere. The focus in subsequent interviews was on the same question but mothers provided more elaborate information about their situations, personal issues, and the concepts that had emerged from earlier interviews. These interviews also provided an opportunity to clarify and verify information received earlier. In

many instances, the subsequent interviews also provided a chance to meet other family members through whom to check the information provided by the mothers. Some mothers were interviewed up to four times during data collection. A few mothers remained in touch with me after the research, some on regular basis and others once or twice when they came to the Shifa Falahee Clinic for medical services.

Audiotapes and Charts No computer program was used in the analysis, as the data were gathered in the Urdu language. First, all the interviews were transcribed in Urdu. Three of the interviews were transcribed by a Pakistani helper in Pakistan; later, on my return to the United States, I transcribed all of the second interviews and eight of the first ones myself. Then I translated each transcribed interview into English on a wordprocessor. To check the accuracy of the process, two interviews were transcribed in Urdu and then translated into English by an independent person at the University of Calgary. This method is called inter-rater reliability or inter-judge reliability and with a high level of correlates establishes credibility of data, which in this case it did.

Participant Observation

Participant observation was another of the techniques employed to gather data for this project. Many writers recommend observation techniques in ethnography because they allow a researcher to understand cultural patterns and behaviors (Clark & Standard, 1997; Goulet, 1994; Wolcott, 1994). For the entire period of data collection I was involved at schools working alongside staff, attending staff meetings, spending time in the classrooms, and participating in problem-solving

meetings with the principals of both schools. As well as participating in formal meetings, I joined the teaching staff during tea and lunch breaks and helped with classroom and outdoor activities. I was involved in the Disability Day functions and a parade in which both schools participated along with many other area institutions.

During my visits to the homes of informants, I noted family dynamics. For this purpose, I kept a journal, and every evening wrote my observations. I also discussed my activities with my key informants on a weekly basis. The technique of consultation with key informants allowed me to understand more about the unfamiliar context in which I found myself and reinforced the idea that I am a learner while those being observed are the experts. The home settings were carefully observed in an attempt to understand the informants in the context of their environments. I learned to understand a great deal by watching the body language, movements, grooming, facial expressions, and postures of those with whom I came in contact.

Documents

I had planned to use two types of documents, formal and informal. Formal documents were the official documents available in local settings, such as birth certificates, diagnostic notes or teachers' assessments. Informal documents are those a researcher creates in the process of gathering information, such as journals and field notes. I spent some time attempting to locate formal documents; however, those I found at these schools were few and unreliable. For example, documents that included demographic data, school records, notes from professionals, and the like,

which could enhance my understanding of the informants and their children, were missing. There were some documents that contained the subjective reports of teachers, but from a research standpoint these were not appropriate to use.

A journal was kept throughout this study in order to remain conscious of the biases, values, and experiences I brought to this study and that might influence its results. All researchers have a frame of reference and a value system that, despite the best intentions, can affect interpretations; I used journal writing to tease out some of my biases. In my case, I make certain assumptions concerning the status of women in Pakistan based on my experience of living in Pakistan. Sociocultural perceptions are regulators of thoughts, feelings, and actions that are imposed by a society or culture. They are different for every individual member of a society and are influenced by the individual's unique experiences and exposures. My perceptions are "contaminated" by Western culture, by exposure to alternative patterns of thought and to various concepts, and by obtaining education in a different system in both Eastern and Western institutions. Personal/individual norms are a variety of regulators imposed by an individual that may differ from the sociocultural norms. My reality involves constantly balancing between two cultures, with my personal norms an attempt to integrate the two cultures in which I operate, which in fact creates a culture of my own that is quite different from that of the mothers of the study.

Visual Ethnography

Edward (1992, p. 4) first suggested that photography is “a simple...truth-revealing mechanism.” Visual ethnography is utilized in many international arenas of research that provide detailed and realistic descriptions of a culture. Collier and Collier (1986) support the use of visual devices. In this study, a digital camera was used to take still pictures of informants, when permitted. Initially informants were somewhat resistant to the camera, but later, when they were relaxed within their homes they became comfortable with picture taking. Only one family refused to give permission to take their picture.

The rationale for using a camera is that often humans are poor observers; therefore, the critical eye of the camera is an essential tool in gathering accurate visual information. Its sharp focus has helped me see more and with greater accuracy. All photographic work is guided by ideas that, directly or indirectly, relate to exploring the culture and settings. Photography is done solely for the purpose of gathering information, and that information is organized, analyzed, and presented in terms of ideas that are hard to verbalize (Harper, 1994, cited in Denzin & Lincoln, 1994).

Subjectivity with Respect to the Culture

A number of ethno-methodological articles have discussed the issue of researchers analyzing their own cultures (Al-Krenawi, Graham, & Maoz, 1996; Bohannon, 1981; Chock, 1986; Greenhouse, 1985). Chock has concentrated mostly on the pitfalls of such endeavors, for example, the difficulties of seeing beyond one's

own frame of reference in examining one's own culture. As a Pakistani woman who lived in Pakistan until the end of the 1980s, I have formed opinions about women and disabilities in Pakistan. In addition, I have worked in the area of special education in both Pakistan and the U.S., and again I am aware of my frame of reference regarding disabilities in these contexts. However, I also recognize the myriad benefits of completing this research in my culture of origin. Western scholars embarking on such an endeavor would encounter language barriers (as Urdu and Punjabi are the spoken languages), cultural barriers (traditionally, a very strong gender role delineation and a relatively closed social system), and religious differences (a strong Muslim society). Moreover, Pakistanis have an array of suspicions about Western modern practices and ways. "*Pardah*" (veil) is a tradition in Pakistani society, and women are wary of being interviewed by foreigners. The point of this ethnographic inquiry is that we have a limited understanding of the Pakistani perspective on caregiving. In order to gain a better understanding of this concept, it was necessary to become somewhat intimate with the mothers of children with disabilities, and a person belonging to the same culture is more likely to be able to foster such a relationship. This issue belongs to neither the realm of objectivity nor that of subjectivity, but rather to intersubjectivity (Olesen, 1992; Tedlock, 1991). If the mothers were to trust me and tell me their stories accurately and fully it was essential that they not feel threatened.

Ethical Considerations

The required ethical considerations were adhered to in this study. Prior to commencement of data collection, ethics approval was obtained from the Social

Work Ethics and Research Committee (SWERC) of the University of Calgary. Confidentiality of identity and responses was maintained throughout. Consent was free and informed. The research subjects were protected against emotional, mental, and physical injury. While mothers are referred to by name (e.g., Shabana, Anila, Mona) in this report, these are not the actual research subjects' names. A discussion of ethical issues also took place with the staff of both schools in the presence of the school principals. Before every interview, the participants were assured of confidentiality and were informed that the study would not harm them or provide any direct benefits. They were also told that they could refuse to answer any question or fully withdraw at any time with no negative consequences, if they choose to do so. None of the participants decided to withdraw. However, during the interviews they asked me to stop the tape recorder when they did not want an answer recorded. They all signed a consent form (see Appendix A). The ones who decided not to participate did not return the consent forms. All documents and tapes were kept in my office, which was locked at all times I was not present.

To participate in this study, parents were required to sign a consent form. These consent forms were given to the staff member who accompanied the children on the bus to their homes, and was to give the forms to the parents. Signed forms were returned to the classroom teachers. Eight signed consent forms were received from Ibna-i-Sana School and three from Fatima Jinnah School. Two parents from Ibna-i-Sana School came in for an interview the very next morning.

One issue that had to be addressed prior to the data analysis was that of translation, a lengthy and tedious process during the course of this research but one that generated some useful lessons.

Translation

The literature does not offer any guidance regarding the translation of interviews in cross-cultural qualitative research. Patton (1990) lightly touches on the issue of translation and suggests that, “special and very precise training of translators is critical” (p. 337) when using translations in research. While there is no literature commenting on the translation of transcriptions, Patton (1990) did recommend that, “when resources are not sufficient to permit full transcriptions, ... only those quotations that are particularly important for data analysis and reporting need to be transcribed” (p. 350). This flexibility in the amount of transcription required gives some relief to researchers with limited time and resources.

Despite Patton’s advice, two issues become apparent in the context of this study. First, it is common knowledge that a great deal of meaning can be lost in the process of translating from one language to another; if not all the data are translated, the data loss may be yet greater. Second, when one conducts qualitative research the outcome is an unknown, and it is through the process of data analysis that one determines the findings, not before that. If the complete interviews are not translated, some data are eliminated and therefore cannot be considered in the research findings. The case is different if a researcher understands the data and then decides to discard it, but to eliminate data before understanding its meaning may lead to inaccurate

conclusions. For the purposes of this study, therefore, Patton's approach seems inappropriate.

Further, one of the ways credibility is established in qualitative research is by a process of "negative data analysis" that aims to include all data sources, whether or not they are contradictory. In the instance of partial translation or data discarding, contradictory information can be lost, affecting the trustworthiness of research findings.

Another consideration in regard to translation is that the data cannot be directly transcribed into a different language, but only into the language spoken by the interviewee. If interviews are written down in any other language they are translations, not transcriptions. For instance, different languages have different expressions, or idioms, that convey intense emotions. These expressions cannot be translated word for word without loss of meaning, and therefore phrases comparable in emotive meaning from other languages must be used to communicate the meaning of the original phrase. For example, one informant in the study showed her intense emotions for her disabled child by describing the child as "*jeejur ki hoti*," which means "a piece of my liver." One can hardly discard a piece of one's liver. When translated word for word, the phrase scarcely communicates anything, and certainly does not communicate the emotion of this mother. An accurate translation would be "a piece of my heart" as in the West the heart is more commonly associated with strong emotions. Substituting the word "heart" in the phrase, then, faithfully communicates the message to the Western reader.

Another example from the transcript occurred when a mother discussed her health problems regarding her breasts as “*mary dood ki naliea gul gui ha*” meaning “my milk pipe has decomposed”(she suffered from mastitis). But this transliteration does not convey her pain or discomfort; rather, it detracts from the intended message. Here again, a deft translation is preferable to transliteration.

Every language has words that have multiple meanings and therefore multiple usages. For example, a very common and widely used word in Urdu is “*acha*,” which has multiple meanings such as *good, okay, alright, and that’s news*. However, depending on the tone of voice, it can also mean *to be cured, just fine, and much better*. For this reason, a roster was kept of common frequently used phrases or words having multiple meanings, which contained a list of plausible meanings of a phrase. When I encountered such a work during the process of translation, I checked its multiple meanings and came up with the phrase that conveyed the intended meaning.

After the data collection was accomplished, the data were transcribed and translated. The next step was the process of data analysis, discussed in the following section.

Data Analysis

The data analysis was accomplished using Wolcott’s (1994) methods of describing, analysis, and interpretation. This method was chosen because the procedural steps are clear and provide structure to the analysis: “The tasks of the analysis are intended to reduce and transform the concrete data in ways that make possible concept formation and the construction of conceptualization. These steps

provide data-reduction and data-transformation from an original concrete state to an abstracted, generalized form which in turn is separated from any particular time, place, situation or person to a 'generic' (Lofland, 1976, p. 269).

In data analysis, categorizing involves a process of linking and sorting comparable domains. Naming them in a theme, possibly in a unique new way, is classification. Research brings out new concepts that are contextualized in a relevant theoretical framework. This organizational step, in which data are assembled into a whole new dimension, is capable of manifesting all of their features for interpretation.

Wolcott's three steps—description, analysis and interpretation—were first applied to the interviews in Urdu and then to the translated interviews, in order to validate the outcomes of the domains and themes in both languages. Each recording was listened to at least two times and each transcript was read, reread, and then translated. Both the Urdu and translated interviews were analyzed with the help of matrices and tables. The first phase of data analysis is based on Spradley's (1979) technique suggesting that the most important unit of analysis in ethnographic research is the discovery of domains. A domain is a symbolic category that can include other categories. Two types of domains were created: database domains, when all the data were treated as one unit from which domains emerged; and separate domains within each interview. Categorization of these two types of domains provided a crosscheck. A domain shares one feature of meaning and is further classified into themes. Folk terms, for instance, were categorized into

domains. In this process, I looked especially for similarities that exist among folk terms. Each folk term was grouped under a domain where it seemed most appropriate. This process needed constant re-evaluation and corrections to categorizing and classification schemes by redefining the emergent themes again and again, because each interview added diverse folk terms with a slightly different spin. Then causal flow charts were created to interpret cultural meanings. The simple causal map provided a visual representation of ideas that emerged from studying data, seeing patterns, and coming to conclusions about relationships between concepts and themes. Classification was then carried out on interview-based domains. Lists of emerging themes were compiled for every interview. From these themes common aspects or sub-themes emerged and were compared to the domains of the data. A crosscheck was performed on the themes that emerged from both database and interview-base domains, and ones not found in any type of domain were re-evaluated and re-categorized. After doing this, I went back to my proposal to match these new domains with the research question. The emerging themes were linked to provide interpretations and possible further hypotheses. Interpretations are discussed in the analysis section of Chapter 5.

Trustworthiness of the Data

Trustworthiness in qualitative research refers to the need to ensure that the data compiled are trustworthy. The process is different from that of quantitative research because qualitative research seeks to understand a social world that is interpreted by the researchers. In a social world there are multiple realities of participants, and this requires different criteria to evaluate the trustworthiness of data

pertaining to those realities (Lincoln and Guba, 1985). Hence qualitative research uses an emergent flexible design to ensure that findings are trustworthy. Various methods of reducing the possibility of misinterpretation are proposed in the literature (Janesick, 1998; Lincoln & Guba, 1985). To increase trustworthiness of data in this study, all interviews were translated into English. The terms used in qualitative inquiry to evaluate the data replaces those of validity, reliability, and generalizability. Four criteria of trustworthiness are applied here: credibility, transferability, dependability and conformability, which are the standards of qualitative research. A brief description, followed by an explanation of how the study adhered to these criteria, is presented below.

Credibility

Qualitative research uses the term “credibility” as an analogue for internal validity. “Credibility” refers to the accuracy of the methods used to collect and analyze the information collected during research. In ethnography, credibility requires the researcher to learn how people think and act in their natural setting and to reflect in the research results the reality and meanings of those studied. Lincoln and Guba (1985) recommend several ways to ensure the credibility of the data while never taking that data at face value: triangulation, consultations, negative case analysis, and member checks. All four were utilized in this investigation.

Triangulation involves checking inferences drawn from one set of data sources by collecting the same data from many other sources (Hammersley & Atkinson, 1983, p. 198). Data-source triangulation is a form of triangulation that

takes place when data are compared with other data that are related to the same event in a different phase of the research. All forms of triangulation provide validation of the data. Another method of ensuring credibility in the current study was to triangulate data collected from different interview sources. For example, interviews with informants, their family members, school staff, and two key informants were compared with each other.

A second method aimed at increasing credibility was **consultations**. My colleagues in Pakistan and Canada provided credibility to this research study in two ways. First, in Pakistan I identified two key informants who provided an opportunity to debrief and discuss the context, and helped me to understand the meaning of cultural practices and belief systems. Second, in Canada my committee members were consulted regarding ethical and legal matters as well as about the methods of sampling and data analysis.

Confidence in the research method is built by “**negative case analysis**,” in which the researcher ensures that all data sources are depicted in the data analysis. Information from various sources may appear contradictory, but all such data need to be included. For this reason, all information gathered through participant observation, interviews, documents, and visual ethnography are represented in this report.

Finally, **member checks** were made so that informants could provide feedback on the data analyzed and the conclusions drawn. One way of ensuring credibility was to member check subsequent interviews of the same sources in which

interviewees elaborated and repeated their stories, and interviews in which other members of the families could validate the mothers' responses.

Two other forms of member checks were employed in this study. The first was accomplished in two ways: (1) the data and interpretations were taken to the sources from which they were drawn, the mothers, who were asked whether they found the results plausible; (2) member check took place when I moved back to Pakistan after I had completed my analysis. I had an opportunity to meet six of the mothers who participated in this study and present them with the individual and collective themes that emerged. The mothers commented on individual themes of their own interviews and gave feedback on them that was then incorporated into my analysis. During these interviews each mother began to compare the themes of her own life with the collective themes of the sample, and her own living situation with the situations of other mothers.

A second form of member check took place during my first visit to Pakistan, when I was invited to go on Radio Pakistan for a two-hour program (Picture 3.1). I was introduced as a student visiting Pakistan to gather data at special education schools in Islamabad. During the program, callers asked questions regarding their concerns about the subject of disability. Many of the callers were parents of children with disabilities, workers and directors of nongovernmental agencies in the field of disabilities or individuals who had a visual or physical disability. This opportunity provided a forum for dialogue with community members and helped me to develop a deeper understanding of Pakistani values, culture and settings.



Picture 3.1. At Radio Pakistan (left to right) with Sobia, composer; newsreader and announcer Zahid Hussain Jatui; myself; and Waheed Sheikh, the senior producer, of Current Affairs Pakistan Broadcasting Corporation.

Transferability

Transferability is a parallel concept to external validity in quantitative research. According to Lincoln and Guba (1985), it is not possible to establish transferability in qualitative research in the same way as one does in quantitative research. The findings of qualitative research cannot be generalized to another time, setting, or context. For this reason, it is recommended that extensive descriptions be offered so that other researchers can judge to what degree a study's findings are trustworthy and may be applicable to their own research. One way this study facilitates transferability is through copious field notes that depict the settings and culture in depth. Ethnographic studies are by their nature a process of discovery of cultural behavior patterns and the relationship between them in societies that are

constantly evolving. As a result, the findings in one study may not be applicable in the same society even over a short period of time, let alone in another society at a different time. Ethnographic studies are analogues to taking a snapshot at a particular time and with a particular instrument (the researcher); to assume transferability to a different moment in time is deeply problematic. This study does emphasize careful description, yet makes no claims for transferability; rather, it aims for analytic generalization, which focuses on the generalization of findings from one case to the next” (Franklin & Ballan, 2001, p. 281). If this study possesses analytic applicability—if similar themes emerge in different times and places with similar conditions and settings, as I believe they would—it is because, even given the fluidity and dynamic nature of human societies, human experiences are at some level universal.

Dependability

Dependability refers to reliability in qualitative research and addresses issues regarding stability and consistency of the data. It required rigorous attention to detail throughout this study. It is for this reason—to insure consistency—that detailed records were kept concerning the conduct of interviews and decisions regarding translation and coding themes.

Comparable results from two or more approaches to the data collection process strengthen the claims to dependability of any single approach. As a result, in this study direct observation, unstructured interviews that focused on the research question, and visual images were all utilized to generate data. Implementing several

methods at once allows the weaknesses of any one method to be compensated by the strengths of another. One of the reasons for keeping journal entries is to record the path to decision-making, schedules of interviews, and the steps and decisions taken to collect and analyze data.

To strengthen the dependability of the study, the decision trail (Franklin & Ballen, 2001; Guba, 1981; Tutty, Rothery, & Grinnell, 1996) was recorded in order to demonstrate the steps taken from the conception of the study, through data collection, to the final analysis. By following these steps, another investigator can determine the trustworthiness of this study.

Confirmability

Confirmability refers to the neutrality, objectivity, or degree of impartiality that a researcher brings to the research process. In order to establish confirmability, the researcher has to recognize his or her own biases, values, and experiences and how they influence the data and the conclusions drawn. To this end, Guba (1981) suggests keeping a reflexive journal. In this study a journal was kept, with entries that focused on understanding the degree of impartiality in the research process and raising awareness, or identifying a lack of awareness, of the assumptions and biases at work. It also contained a variety of other information, such as data collection and analysis procedures and decisions in regard to them, and personal notations.

Chenitz and Swanson (1986) indicate another criterion of confirmability, which entails comparing the findings of the current study with the findings of other research studies found in literature. The theme Gift of Allah was unique to this study:

however, religious, intrapersonal and cultural realities domains were present in other literature with different themes. In the intrapersonal domain, the theme of hoping for a cure by using traditional healing interventions were common in Arab, Indian and Pakistani literatures. The role of motherhood did not appear as a theme in either Western or Eastern caregiver literature. Mothers of children with disabilities used social support but in Western literature, most studies implied that those were formal support systems rather than the informal supports such as spouses, neighbors and extended family used by the mothers of this study. Furthermore, under the cultural domain, themes such as caring for extended family, and the concept of *pir/faqueer* were new to the Western literature.

Chapter 4

FINDINGS

This chapter reviews the findings related to the daily life experiences of mothers in Islamabad, Pakistan, who provide care to children with disabilities. This ethnographic study aims at gaining an understanding of how those mothers cope in a non-Western culture with low socioeconomic resources. The stories of individual participants offer a panoramic scope. These brief narratives open up a small window into the lives of these mothers, revealing them as real people with real day-to-day difficulties that they deal with. These narratives, offer some insight into their culture and lifestyles. The stories are reported in Appendix B.

This section will present the three domains that emerged from study of the lives of these mothers of children with disabilities. The following section focuses on three major domains: religious beliefs, intrapersonal issues, and cultural realities. Under each of these domains emerged many themes that in turn have many different aspects. The primary question of this study was: **What were the daily life experiences of mothers who have children with disabilities?** A discussion of the main domains and themes in the data follows after demographics.

Demographic Data

The demographic data are represented in Table 4.1 and in a different format in Table 4.2. There was not much demographic diversity among the informants. All the mothers were married, lived with their spouses, and had more than one child. The respondents had been married from 14 to 38 years, with average duration of more than 21 years. Nine respondents lived in Islamabad, the capital city of Pakistan. Two respondents lived in the outskirts of the city. Table 4.2 shows that the majority of the mothers (36%) are in the age group of 30 to 35 years old. Five mothers (45%) had primary school education, two (18%) were totally illiterate, and only one mother in this sample had a college education, which yielded an average sample education of about fifth grade. The majority of mothers stayed home, except for one who worked outside her home. Of the children with disabilities 40% were 11-15 years old; the second largest group, at 33%, was the 5-10 year old age group.

Each mother had three to ten living children, with a cumulative total of 55 children and a sample average of five children (stepchildren were not included). Two respondents had three children with disabilities and nine mothers had one child with a disability. Of the children with disabilities, ten were boys (67%) and five were girls. Only three families did not have any extended family member living with them. Income below 10,000 rupees was considered working class. One family income, which was a little above 10,000, was considered in the middle class range; the rest were in the lower income range. (Note: Fasal's family income was also in a slightly higher range because it was reported as the combined income of four people)

Table 4.2

<u>Characteristics of Mothers and Children</u>		
Variables	Percentage(%)	Size(n)
Age (years) of mothers (n = 11)		
30-35	36%	04
36-40	18%	02
41-45	18%	02
46 and above	27%	03
Educational background of mother (N=11)		
Uneducated	18%	02
Primary (1-5 years)	45%	05
Secondary (6-10 years)	27%	03
Collage (11- 14 years)	09%	01
Mothers' employment (n= 11)		
Employed	09%	01
Unemployed	91%	10
Age (years) of children with disabilities (n =15)		
05-10	33%	05
11-15	40%	06
16-18	27%	04
Sex of Children with Disabilities (n=15)		
Male	67%	10
Female	33%	05
No. of households (n = 11)		No. of family members (n = 108)
1 household		1
7 households		7
1 household		1
2 households		2
The average is a little less than 10 family members living in a household.		
No. of mothers (n = 11)		No. of Children (n = 55)
4		3
1		4
2		5
2		6
1		7
1		10
The average is 5 children per mother		

1. RELIGIOUS BELIEFS DOMAIN

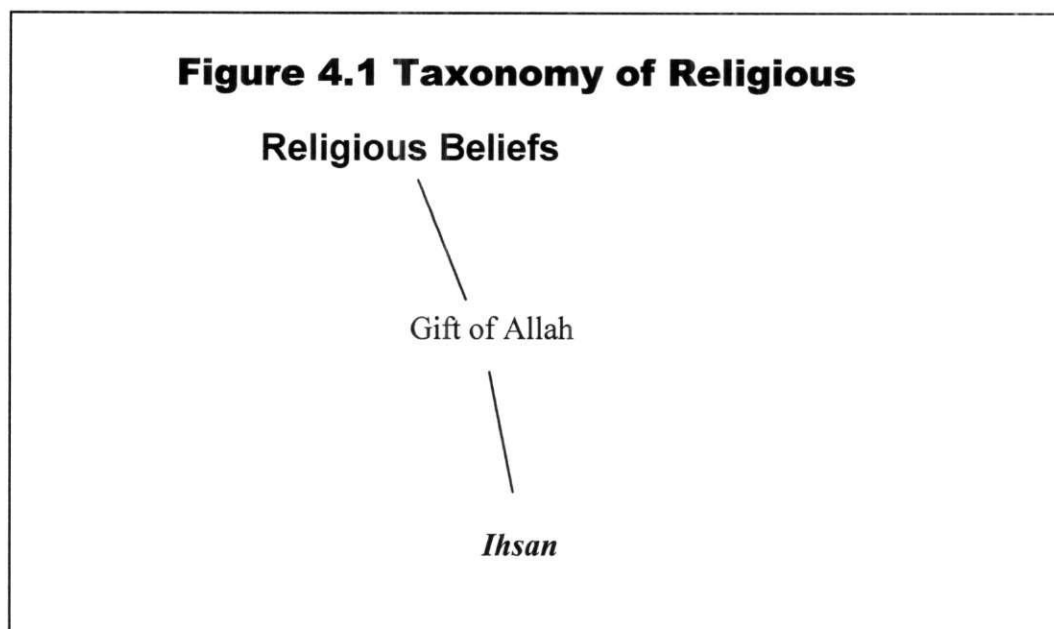
Pakistan is an Islamic country whose population is 95% Muslim. Hence most religious practices are centered on the teachings of the *Koran* and the *Hadith*. The Koran (sometimes spelled Quran) is believed to be the word of Allah revealed to the prophet Mohammed and written during his lifetime. The *Koran*, as interpreted by the words and practice of Mohammed, is known as *Hadith, or Traditions*, and contains the final teachings of God (Khan, 1990; Mernessi, 1991; Rouf, 1977). The Koran is the foundation of the social order that dominates all aspects of life in Pakistan. However, there are major inconsistencies in practices because of diverse interpretations of the Koran. The interviews revealed a powerful theme that related to religious beliefs; the child with a disability as a gift of Allah, meshed with the concept of *ihsan*. The concept of *ihsan* is further explored in Chapter 5). Figure 4.1 presents a simple taxonomy of this domain.

Theme 1: Gift of Allah

In the religious domain, “gift of Allah” was the primary theme. All mothers and their families referred to their children with disabilities as “gift of Allah,” “Allah given,” “Allah *log* [people],” and “*Allah walla* [belong].” These phrases were used very frequently by all respondents. Parents were appreciative of what Allah had bestowed upon them with regard to children in particular as well as life in general. The following quotes depict the essence of the finding as gift of Allah.

This [points towards the child with disability] is a gift of Allah.

Allah has given these children [with disabilities] to us and we thank Allah for that.



Some mothers of children with disabilities were also grateful to Allah for having children who were good-natured:

This was Allah's kindness that Allah has given me very nice children, kind, obedient, and they listen.

Some parents stated they were thankful that Allah had given them children, whether disabled or not. Getting married and then having children is a norm in the culture, and any deviation makes one appear inferior. The importance of having children becomes apparent in this remark of a mother with three children with disabilities:

It is obvious that it would have been more painful not to have any children—thank you Allah.

Parents who have a child with a disability see no other way but to love and care for that child. None of the mothers expressed feelings of guilt or resentment; however, two informants, a sister and a father, did question Allah concerning their child's disability, although with fear and humility. Notice that these quotes convey some questioning of disabilities along with maintaining an attitude of thanksgiving:

We thank Allah that Sadat is our brother—he is so nice. We do question why is he this way or how will he get well but we still thank Allah.

Alhamdulla [Thank Allah]. She is Allah's gift and what He has made—I cannot doubt his creation. She could have been worse, by the will of Allah and I could have done nothing. We are all helpless in front of Allah. We can do nothing except question him, that too, humbly.

These narratives demonstrate informant's strong belief that having children is a blessing from Allah, even if those children have a disability. This perspective is strengthened by the concept of *ihsan*, which provides a rationale for this acceptance and continuous commitment to care.

Ihsan

The concept of *ihsan* refers to doing a good deed; more on the concept of *ihsan* in Chapter 5. These following narratives explicate some ideas about *ihsan*:

Why Allah gave us a child with disability was to test us and to see if we get upset with him or scold him...[if we do] then it is not going to go in our favor.

Only my Allah knows. There is some good for me—in the next life. I do not know about this world. I may get paradise because of this child.

The belief is that to care for a disabled child will result in Allah's conferring favor in this world or the next. The concept of *ihsan* is also mentioned in regard to other people who take care for the child, whether these be neighbors or a master who lets a family move into the servants' quarters.

Neighbors do *ihsan* by considering him like [their] own son. When he goes down—they see him, they make him sit in their house and then inform me that he is at their place playing. Sometimes he gets out of the house and goes to the market, they go after him and get him for me.

We found this house but they would not take anyone with children. And for her sake [child with disability] they agreed to give us accommodation. It is their *ihsan*. They are kind people and take care of us and tell me to visit her school to find out about her.

The father quoted immediately above was very appreciative of the homeowner who let his family live in that owner's servant's quarters. The family had immigrated from a village to Islamabad because they wanted their child to attend a special education program available only in the city. The landlord agreed in the spirit of *ihsan* because the child needed to go to the special school and because of the blessings from Allah he may receive.

I say plainly that she is my daughter, just make her well and it will be *ihsan*.

Sometimes parents cling to hope of normality so tenaciously that they want the schools to do something miraculous so that the child will get well in the spirit of *ihsan*.

In conclusion, the spirit of *ihsan* asserts that a child's disability is a test for parents and that parents are given the capacity to care that child. Through *ihsan* parents and others can avail themselves of Allah's reward.

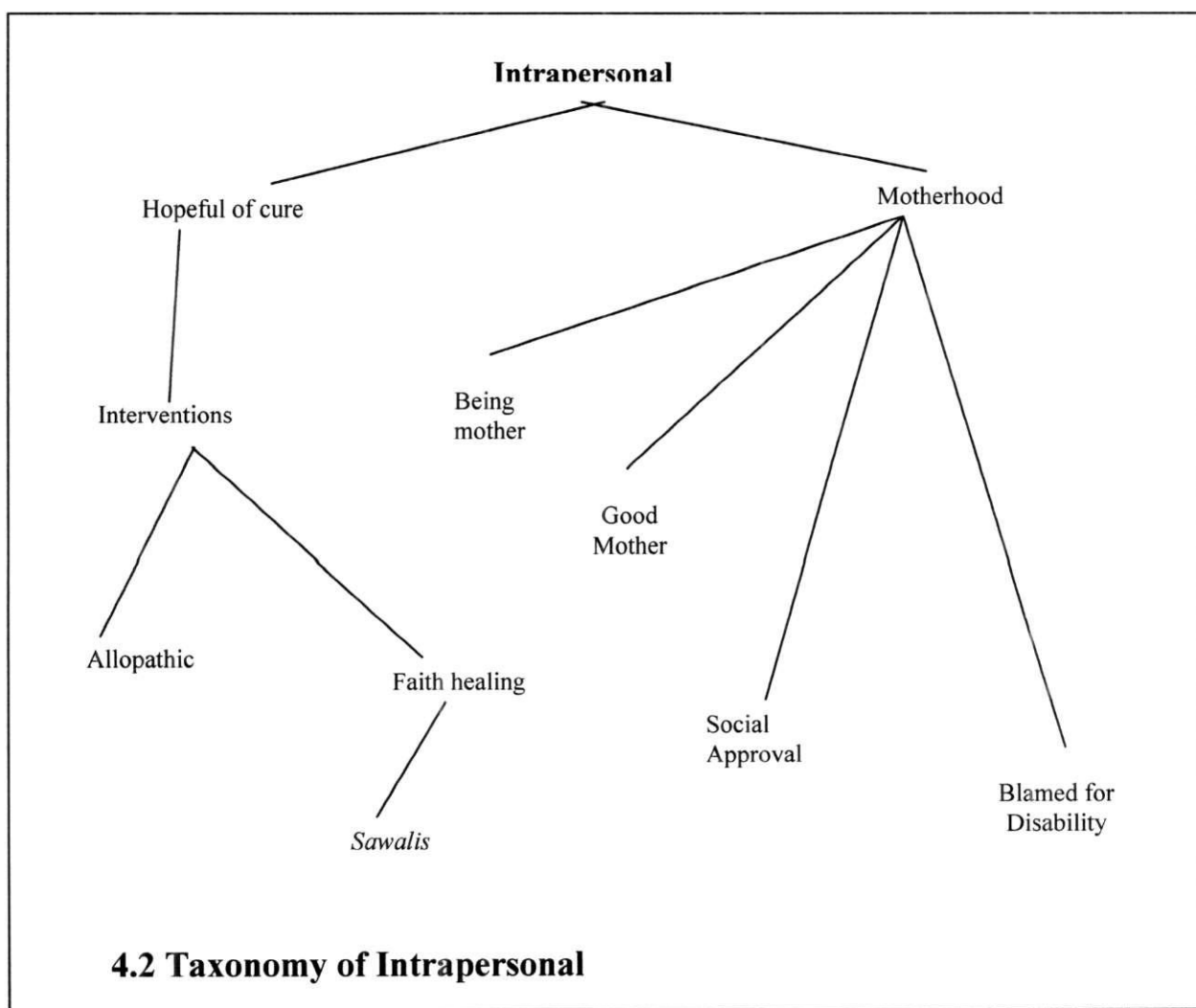
2. INTRAPERSONAL DOMAIN

The second domain deals with the intrapersonal issues that emerged from the mothers' narratives. Two major themes were identified within this domain: "hopeful of cure" and "motherhood". "Hopeful of cure" has one aspect, "intervention" which is further elaborated into two dimensions, "allopathic" and "faith healing". "*Sawali*" emerges within the dimension of faith healing.

The motherhood domain was compiled from the numerous and diverse folk terms used by the mothers in describing themselves, their social support, and their culture. This domain emerged with four aspects: (1) being a mother; (2) being a good mother; (3) social approval; and (4) mothers are not blamed for the disability. Both social approval and being a good mother are on a continuum rather than forming a dichotomy, because both are fluid and depend on the circumstances of these mothers. For example, when the child wandered out of the house into the streets, the woman would ask, "What kind of mother am I that I was not paying attention?" Her belief in herself as a "good mother" was put in dispute. At other times, when a neighbor praised the same mother for putting the child with disability into a special education

program, the mother considered herself a “good mother.” In the same way, the social approval of others shifted with social expectations and the woman’s performance of the mothering role. This domain has many overlapping aspects, which were expressed within the subtleties of language.

Figure 4.2 outlines the taxonomy of the theme of intrapersonal issues.



Theme 1: Hopeful of Cure

In the current study, the mothers were very hopeful of finding a cure for their child with a disability. The narratives also revealed that hoping for a cure provides the mothers with an effective way to cope. Most mothers in the sample were hopeful of their child being cured and tried a number of different modalities to achieve this, such as allopathic, and homeopathic remedies, traditional healing, and Koranic therapies. Notice in these quotes a recurring theme of hope in the pursuit of a cure.

I have faith that my son will get well. I have gotten him checked at mental hospitals and then his Abbu [father] took him there too. They told us that his brain would become better with time.

One belief sometimes expressed by interviewees was that a change of location would help a child with a disability to find a secure and better life. Mothers were willing to make a sacrifice to send their children overseas, as reflected in the following narrative.

My brother lives in Germany, [he] has suggested that he adopt and take Arslan with him. He was here for two weeks and asked me to get his papers from school and get a complete case history from the doctor. It is no joy to send him overseas but I will see him off to give him a better future. For that I will send him off with lots of pain and sorrow. My brother gives me hope that Arslan will get well in Germany.

Mothers generally were very involved in looking for a cure, going to different kinds of healers and trying all the modalities available to them. The sense of constant pursuit for cure is evident in these quotes:

Then we showed her in the Hospital Complex, completed a course of homeopathic medicine, and made her eat almonds and so forth. And took her to many shrines or to *faqeers* [healer], anybody they told us to take her to.

We have faith in our Allah that He will do him good—Allah may give him more. It is possible that Allah improves him. We will say he becomes absolutely normal. We pray all the time to Allah that “Allah makes him normal”.

Notice also the sense of ambivalence in this response, the uncertainty and helplessness regarding finding a cure for the child. However, the parents have conviction that Allah somehow will improve the child’s situation. Most respondents simply want their children to get better with Allah’s blessings. As one mother put it, “We have hope that with Allah’s will, she will be cured.”

Interventions

The healing interventions typically sought out by mothers consisted of allopathic and faith healing methods. The respondents of this study reported repeatedly trying different healing modalities, seeking a cure. Figure 4.2 illustrates the taxonomy of the intrapersonal domain regarding “hopeful of cure”. Nine respondents in the study were ever-engaged in assessing treatments, such as allopathy, homeopathic medicine, Koranic therapy, herbal therapy, amulets, or taking the afflicted to shrines to improve the disability’s symptoms or increase the child’s abilities.

Allopathic medicine. The mothers visited hospitals when their children got very sick. These narratives give some idea of the general feelings regarding allopathic medicine:

She used to remain sick all the time and I used to take her to the doctors in the hospital. At that time, I could pick her up and take her to the hospital—my children said to me why do you stand and run to hospitals. They do not see people who are in better shape than her—why would they see her in such a bad shape?”

We gave those medicines, well the medicines they gave were Valium and diazepam. That was it, to give half a tablet, half a tablet, I said what is this—this is an addiction not a treatment. This will keep her sleepy. I used them a lot...then I have absolutely discontinued them. I have stopped giving any medicine since the year 1990...

It is evident from these quotes that mothers who utilized allopathic services sometimes gave up for the reasons mentioned. Other mothers were very satisfied and have been going to the same clinic because it meets their needs.

A lady doctor sits in the clinic. We have been consulting her from the beginning and if it is serious then we go to the doctor she refers. They are the ones who have been providing treatment to Taqi.

Faith Healing. Many parents were not prepared to eliminate faith healing as a possible means of cure. Their endless efforts can indeed become, as one father put it, “the family’s hobby.” Parents would not only try different modalities, but also went to different healers for a cure for their child. In this state of vulnerability, the parents would take seriously anyone’s advice or claims and would drag their child onto public transport to faraway places in the search for a cure. Prayer is one constant, as this mother stated:

Mostly I do homeopathic medicine. In fact, I only do homeopathic treatment and have given up other treatments.... Now when he gets sick, like today he is sick with fever, I will show him to a homeopathic doctor, however, in every *namaz* [prayer] I say a prayer for him that he gets well.

Some parents told of small but important successes through faith healing, such as one instance in which the mother took her child to a *pir* [faith healer] for lack of control of his bladder and bowel movements.

There is a *pir* in Peerwadhi area, he wrote a *taveez* [amulet] and asked me to put it around his neck. After that he [the child] was cured.

After a few months of wearing the amulet around his neck the child demonstrated bladder control. The mother believes that the amulet has cured his condition, and this small improvement in her child's life offers her hope. This narrative illustrates a major success due to faith healing:

By Allah's blessing it happened—we went to one *pir*. He prayed and she started walking. Slowly it started that her feet were formed, then her shin and calf were formed, legs and buttocks were formed. Where she could not sit—she was walking by Allah's blessing.

Then there were parents who did what was suggested even though they knew that their child's condition was not curable; to follow the advised course of treatment made them feel good and eased their mind:

.... some tell us to recite verses of Koran. We believe in that but we know that the kind of problem they [the children] have is not curable.

After having experienced several forms of interventions, parents tended to settle for a particular approach that they believe will work for them and their child. These parents will also take their child to faith healers for daily illnesses. They devote a lot of time, effort, and money to the pursuit of a cure. If nothing else, it provides them with some piece of mind. However, generally parents were disheartened with medical treatment.

Sawali (Supplicant)

People who visit different shrines and *pir* (faith healers) asking for a wish to be granted are called sawali. In some of the narratives they do not specify their own role; however, they approach healing practices as *sawalis*. The following narratives have articulated the role of sawali very well.

Although with Atif—his madness gets out of control. Still we are *sawalis* going to healers, and *faqees*; and have not given up hope for his cure. We have not given up.

These families are engaged in faith healing practices on a regular basis. They go to shrines as one might visit a doctor's office when one is sick. In fact, they visit frequently in the hope of finding a cure, although most of the time they are unsuccessful. This narrative shows some of the frustration and vulnerability on the part of such parents.

I have done everything, which has been told to me by the doctors, homeopathic doctors, and *pirs/faqeer*, but there is no benefit.

Sawalis, *pir* and *faqeer* are very culturally embedded concepts and practices. Chapter 5 will give more details of the concept of *sawali* and how it is practiced.

Theme 2: Motherhood

The mothers' beliefs are very much influenced by their religious faith and the cultural realities of their context. These beliefs and realities also affect their societal values, and in particular their judgments of each other in the role of mother.

Motherhood has four aspects: being a mother, good mother, social approval, and no blame from social supports, such as spouses, neighbors, and extended family members. These dimensions intertwined with each other.

First, **being a mother** was important for these women, despite having borne a disabled child. The mother who had three children with disabilities was clear that “not to have children is obviously more painful” than what she had: “one can hang on” to children with disabilities, but to have no children at all was “painful.” At times the disability is considered a special blessing, with the mother believing she has a special child. As one mother stated, “Our families believe he has good fortunes.” Another mother did not feel the disability was an issue and gave an example of family members who also had had children with disabilities that grew up to become *faqees*. Another mother who had five daughters stated:

I have daughters, if I did not have them what would I have done?

Again, although having girl children was not perceived to be as good as having boys, simply having children gave these women a purpose and a role that was extremely

important because of societal pressures and female role expectations (discussed in Chapter 5).

Second, these mothers believed that they were **good mothers** because of the respect they earned from fulfilling this role, from husbands, extended family, and neighbors. The narratives of the informants demonstrate that all mothers were validated by others and considered themselves “good mothers,” which establishes their competence. For example:

My husband thinks I am a good mother. He compares me with my sister-in-laws and observes how nicely I take care of my children.

My families, which include his paternal and maternal sides, are of the opinion that I am a good mother, that's why Allah has blessed me with such a son.

This has never been said to me that I am a bad mother, [but on the contrary] good. He [her husband] knows I am an obedient wife who stays at home and works.

There was universal acceptance of disabilities among those interviewed; as mentioned, having a child with disability appeared to give the mother a sense of purpose. Becoming a caregiver in addition to being a mother elevated them to the status of “good mother” in the opinion of others and themselves. In fact, the ethnographic evidence indicates that these mothers gave their children with disabilities more attention and care than their other children. The role of caregiver had given them an identity that granted them an additional purpose in this world for which they would be rewarded in the afterlife. The worldly rewards of respect, recognition, and importance were immediate and tangible; however, the eternal

rewards that they expected to receive for their pain, efforts, and sufferings were intangible and everlasting.

There was a strong sense in all the interviews that the mothers felt they were entrusted with a special responsibility. As one mother expressed these sentiments:

Allah only knows why He has given me this responsibility. Maybe Allah knew that I am capable of fulfilling my responsibilities and that's why he has given it to me.

The third aspect of motherhood is the **social approval** these mothers received from their interactions with social supports. This social approval was for a job well done as mothers and caregivers. The informants indicated strong feelings of competency as parents and caregivers as they satisfactorily fulfilled the demands of their multiple roles. One mother who did not have a good relation with her husband (see section on social support below) –he did not care for his children and lived with his in-laws—said that nonetheless:

Yes my husband supports me, he [is] the same as he use to be before the birth of this [disabled] child.

This narrative brings out the extended family sense of respect for mothers:

My own family respects me because I am a mother of a child with a disability.

This interviewee expressed the sense of social approval received from neighbors:

People appreciate me for looking after my children. This is the thing, when people appreciate me for keeping the kids so well I feel happy and peaceful.

The mothers took pride in their parenting skills:

Everyone appreciates me and thinks that I alone can do it. All say that I can handle him and take care of him very well.

Everybody says that I handle my child well and give my time to him.

The fourth aspect of motherhood was the frequently expressed belief that mothers are not **blamed** for bearing a child with a disability. As already discussed, these children are believed to be given by Allah, and therefore their mothers do not experience blame in any way. As stated by one mother:

No blame—not at all, this is Allah’s given, it is not in anyone’s hands.

In conclusion, two relevant general observations emerged from the narratives. First, religious beliefs and cultural realities strongly influence the role of the mother and contribute to the significance, perceptions, and approval experienced by mothers who care for a child with a disability. Second, these mothers feel appreciated, respected, and honored by the informal supports in their lives. These mothers carry out their role with a high level of competency, purpose, and devotion, and in turn they believe they will receive great respect and blessings from Allah.

3. CULTURAL REALITIES DOMAIN

The third domain places emphasis on the cultural context of these mothers. The cultural realities domain encompasses the practices, values, and social support systems that influence the mothers in this study. It takes into account the caring

behaviors, the mother's health, and the concept of becoming a *pir*, or faith healer.

Five themes emerged in the cultural realities domain:

1. Caring
2. Daily routines
3. Health
4. *Pir/Faqeer*
5. Social support

In **Figure 4.3** the taxonomy of cultural realities is presented to give the reader a visual representation of this multifaceted domain. This is the most intricate and complex domain of this research because within each theme there are many aspects and dimensions. This domain locates the participants of the study within their context and in so doing helps the reader to understand the multilayered beliefs, values, and practices of the informants. Findings concerning the main five themes in this third domain follow.

Theme 1: Caring

Caring in this study refers to the day-to-day chores of taking physical and emotional care of children with disabilities, as well as other demands on the mothers' time and energy. In addition to caring for children with disabilities, these women provided care to their immediate, often large families; they stayed in contact with and maintained relationships with many extended family members; and they shared their family home with extended family members.

Caring falls outside the scope of the daily routine theme because of the additional responsibility that attends the rearing of a child with disability. Most of the study respondents' lives revolved around their home and families, as ten out of

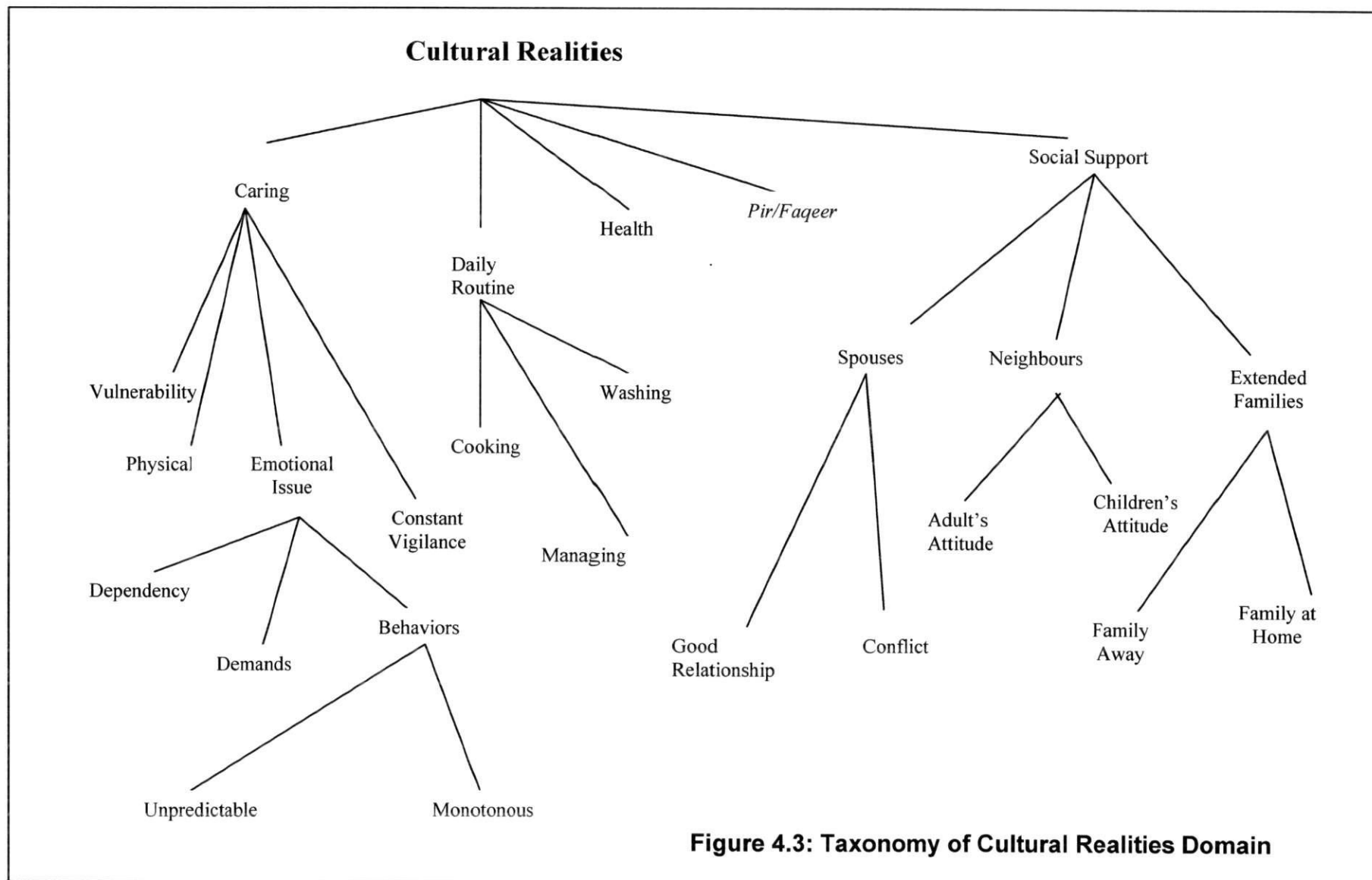
eleven did not work outside their homes. The following section will clarify the caring responsibilities of the mothers in this study.

Caring for a child with disability

Caring for a child with a disability required these mothers to provide care in four dimensions: vulnerability, physical work, emotional issues and constant vigilance. These mothers were very committed to caring for their child, as these children were extremely **vulnerable to illness**. Curative measures were taken for two reasons: for mundane illness and in pursuit of a cure for disability. The second curative measure, as we have seen, was evident in the sections dealing with the dimensions of “hopeful of cure” and “faith healing” and therefore will not be presented here.

The mothers described their child’s medical condition in explaining the child’s vulnerable state:

With a little carelessness, Kashi [the woman’s second child with disability] gets sick and is admitted to a hospital. We kept getting treatment for her and now we have gotten enough treatments from doctors. Caring for her is like caring for a sick three-year-old child, keep this in your mind.



The mothers described the hardships in their experience of raising a child with a disability who was very vulnerable to illness:

It is very difficult raising her...she used to get sick all the time. Village water did not suit her and she had stomach problems. For months she would have dysentery and it was very hard to get rid of that to make her well. Then we got her treated and moved here. Nobody was there to help me look after the little sick girl. We ended in my in-laws' house. The water did not suit her, she use to get cold and congestion and because of that she had difficulty breathing. Then her stomach got very sensitive. When she ate [anything other than] her usual food she started throwing up and had dysentery.

Note that this mother stated that she had no one to help her in providing care to her sick child. This was a task that she completed while caring for other young children and performing the household chores. Another mother spoke of her child's vulnerability to illness:

When he showered himself [the mother was not available to give him a shower] he got flu. Fever about 104 degrees, it took three, four days before the temperature went down, along with that pain started and we took him for a check up. He has been at home for the last 5-6 days due to fever and pain.

The second aspect of caring for a child with a disability was the amount of **physical work** needed to dress, shower, and complete other activities of daily living.

This is illustrated in the following:

I give her a shower, she is so big but I have to give her a shower.

He started [saying he has to go to the bathroom] after seven and would still soil his clothes and vomit—I have had some very tough times. Those years were morbid.

These children were unable to perform the tasks of personal hygiene for themselves and at times were incontinent. Over and over mothers describe the physical work required by these children. This narrative(s) capture some of their physical work:

“...[REDACTED]... If I ask him to go wash his face and hands...he does not wash them well.

So I wash his face and hands, cut his nails, do up his buttons, change his clothes and give him a shower.

“...[REDACTED]... One mother of a teenage daughter had to supervise her very closely at the

time of her menstrual periods, as the child could not manage herself. This monitoring took place in the context of a very busy 17-member household, and was only one of the woman's many chores.

I have to see to that also. We have an all-male household, so I explained to her all the ways and precautions. I get her ready first thing in the morning. First, even before her period starts, I keep asking her “are you well,” she answers “yes.” When they start she gets me. I take her and attach her pad, change her clothes, then she stays in bed. This is another big worry. I have to see that she gets changed and cleaned during the night. At night, I change her and then she goes to sleep. When she has to go to the bathroom she needs setting up [her pad] again. Early morning before breakfast, I wake her up and let her use the bathroom and set her up before everyone else can take time using the bathroom. Then she goes to lie down in her bed and I start cooking breakfast. By the time I finish breakfast work, it is her time to go again.

“...[REDACTED]... This process also involved dressing and cleaning the children before the bus

arrived to take her or him to school, in a context where there was no hot running water; mothers had to heat water in a big pot and mix it with cold water in a bucket before they could give the child a shower. This narrative described a routine, which all these mothers go through:

When I heat the water and ask Fasal to get ready to take a shower, he goes in and in a minute he is back after running all the hot water out. Then I have to go again and give him a shower by cleaning him thoroughly and massaging oil on his body. I have to remind him constantly “now wear your socks,” and then I put on his socks myself because he cannot. He wears his own clothes and can button, he needs someone to put on socks, and...I tie [his shoes].

Mothers who had three teenage children with disabilities had become overwhelmed by their caring responsibilities, as they grew older and less physically able to cope:

I have to do everything for these three children. They cannot do anything. I used to give them a shower every second day and was able to give showers to all three in one day, but now I just can't find strength to do so. I plan on giving one child a shower a day, they are big and old now.

Another mother described caring for her eight-year-old as equivalent to caring for a small child:

I give him shower, he is so big, but still I have to give him a shower...He is eight years old but he needs care as a little child. Before going to school he needs one hour to get ready for school. He cannot eat solids or fried food. He needs lunch that is soft that he takes with him and that requires a lot of work. Then he does not feed himself, so someone has to sit with him and make him eat—one bite at a time. It takes an hour or 45 minutes to feed him.

The third aspect of caring included three dimensions of **emotional concern**: lifetime dependency, fulfillment of the child's demands, and the child's behaviors. One major emotional concern of the mothers of this study was the **lifetime dependency** of a child with a disability. In addition, as noted above, the children

were very vulnerable to illness, and this was emotionally stressful to mothers. The following quotes express the essence of these mother's emotional concerns regarding dependency issues:

I and all my family are very concerned and ponder what will happen to this child. I will die and who will take care of him? We do not have enough resources to send him overseas. Thinking about this problem has given me a constant headache. I don't think [as much about] my normal children as I think [about the disabled child's] future.

It is very worrisome for me, the boys [siblings of a child with disability] will get married and what will happen to him? I worry for him and keep thinking what will become of him. Times are bad too. Without parents nobody looks after [as person]... I have been of the opinion that first he dies and then I die so that he won't be thrown out.

These quotes illustrate the strength of the mother's emotional state and show the gravity of the problem and the depth of their concern. Most of the parents of female children with disabilities expected their daughters to marry and that would resolve issues regarding life long responsibility and dependency.

Parents pointed out they **fulfilled the demands** of their child with a disability more readily than those of their other children. Sometimes these children make demands that are inappropriate, and if these demands are refused or not immediately met they will throw a tantrum. Mothers described their child's demanding behavior as follows:

He demands at odd times to go outside. He wakes up during sleep and demands...to be taken on a ride. Then we take him to one of our many relatives here... at late hours still we take him—otherwise he gets upset.

She is so stubborn and if she does not get her way she gets angry.

We provide for everything he demands. See, this closet is full of toys and things that cost three hundred, four hundred, and five hundred, what he

demands we get him. Other children who are normal know that we cannot get them these things and they do not demand. But he is like this, he does not understand and he gets mad.

Another dimension of emotional concern was the **behavior** of these children. These families constantly required great reserves of tolerance and patience as they dealt on daily basis with some very difficult behaviors from the child. Some parents experienced the behaviors of these children as unpredictable; for other parents they were so monotonous they provoked irritation. Both kinds of behaviors constantly tested these parents. Some mothers gave examples of these unpredictable behaviors:

Anything can upset him—if someone does something that he does not like, he throws a tantrum. ...I feel for him, and in this mounting tension I wonder what kind of parents are we?

This mother's narrative presents the monotonous behavior that frustrates and irritates her:

Seven eight years he did not sleep at all, day and night he constantly rocked, sitting and standing, banging his head. Now...he sleeps, but with a little disturbance he wakes up and starts banging his head. He cannot imagine sleeping in the daytime... just sits and rocks. Any place he sits, he bangs his head on the walls. His shoulders are all bruises; I can tolerate it to some extent and [then] I yell at him, but nothing—he has made the sofas wobble, beds wobble, and every piece of furniture in this house wobbles because of his rocking. No normal human can bang as much as he does. It sounds "thaya, thaya." He puts all his force in striking the wall. When he walks he rocks. He rocks sitting, standing, and walking and all the time...maddening rock...

The final aspect of emotional concern deals with **constant vigilance** on the part of caregiver, to ensure the safety and security of the child. These mothers generally did not trust anyone with their child, forcing both mother and child to stay

at home. This constraint contributed to mothers feeling fearful and tense, fearful when the child went out; and tense when the child constantly stayed at home.

Mothers reported that other children called their child names, mistreated them, or fought with them, which would emotionally drain the mothers. The mothers described their experiences in these words:

Raising them is hard because neither can we send them outside alone to run errands nor can they stay at home alone. There is this danger that they might do something wrong. For example, during the winter we cannot leave them while gas heaters are on. We are scared that they might put paper in them and set the house on fire. However, when I am at home they do not touch anything. They have this much sense, that mother is home. However, when they sense that I am busy praying and cannot see them or check them, then they make mischief. They fight also.

He is very stubborn; it is very hard to get [him to do] anything. Raising him is difficult because he requires more care and one has to be attentive to him all the time so that he does not go outside. Besides, I get mistrustful that some bad thing will happen to him when he goes outside.

Another reason for parents to be constantly vigilant was that their children with disabilities had little sense of right or wrong and would randomly act inappropriately.

He used to soil his pants many times a day at school and at home. The thing that worries us about him is his being incontinent, [he] makes mischief, bothers us a lot, he has broken very expensive things at home. He gets out of control if things divert slightly from what he wants. He hardly listens.

Some parents were scared to take their children to open, crowded places. For example, one mother narrated her concern:

We took her one or two times [of the bazaar] and one time she got lost, then we stopped taking her. ...One time we took her, we went to do shopping for clothes, and she disappeared. We looked for an hour or so to

find her...a wagon driver found her in Karachi Company [a high-traffic, busy marketplace]. I was very anxiety-ridden. Her Abbu had the courage to look for her, I did not have the heart to do or think [anything].

These quotes demonstrate that mothers put a lot of effort into providing physical care such as showering, feeding, and cleaning. Providing emotional care to children with disabilities was stressful, but these parents never made it an issue or labeled their caring a “burden,” although all aspects of burden discussed in the literature were present. Rather, mothers associated themselves more closely with the role of mother and found additional purpose in life through their caring. Caring for children, even if they were disabled, gave the mothers pride.

Caring for extended families

The second aspect of caring comprises care of extended family members that shared accommodation with these mothers and their families. These extended family members required food, clean clothes, some financial support, nurturing, and guardianship. Mothers and their immediate families were very involved with these members, not only providing material necessities but also looking after their well-being on many levels. The extended family members participated in all aspects of the immediate family members’ life struggles, and therefore became part of their triumphs and failures on a daily basis. This involvement was reciprocal.

Caring for extended family meant increased household chores for these mothers. In this sample most of these extended family members joined the mother’s family in order to pursue better opportunities, such as education and jobs in urban areas, and hence the mothers wanted them to make the most of their time. For

example, one morning when I visited Tuba, she was mopping the whole house by herself while her children and her husband's niece and nephews were still sleeping. When I asked her why did she not wake them up to help her, she stated that they have been studying late the night before and she thought it was not necessary to wake them when they only had one day to catch up with their sleep.

This mother lived with two brothers and their large families, and it was her responsibility to cook dinner for the whole family. Some mothers also looked after their own parents who were old and frail and lived with them:

My sisters-in-law don't have to do anything for my mother. If I am not there to do, she [the mother] sits and waits for me. She depends on me and tells them that when I return home I will offer her food, change clothes and everything else.

Another mother provided care to her father-in-law. She referred to him as "grandfather". Women seldom call men by their names, especially their husbands, fathers-in-law, or brothers-in-law. Usually they refer to them by terms that describe their child's relationship to them. This women's father-in-law was disoriented and weak and could not perform most personal chores. The mother described him in these words:

I look after grandfather. He was okay before, but now his mental status... he had a heart attack. And after that he developed a mental disability.

These narratives indicate that the mothers provided opportunities to younger generations in addition to providing care to aging parents. There were three different groups that received care on a daily basis, then: their own families including a child

with a disability; young members of extended families who worked to obtain better opportunities; and aging members of their extended family that needed support.

Caring for extended family living away

The final aspect of caring relates to extended family who lived in their own houses but who are frequently visited. As well, these family members may come and stay with the mothers in this study.

One mother informed me that she goes to her parents' house, stating, "I go for many days." One family's son lived in the village with his grandparents to avoid the city environment, to obtain religious education, and to work. By way of introducing his family, the father in this case mentioned his son who lived away:

I have a son Amir, he lives at his grandfather's and grandmother's house ... my son Amir is tall and big. They [the grandparents] told him that we [his parents] do not want to hear any complains about [him] and you have to go to *masjid* [mosque] to get religious education. He works in the village. The city atmosphere is not good—so I thought he [would] not get into bad influence, at least like this he will go to *masjid* and work.

In the following two passages, the mothers were conversing about family and friends living in villages that they visited. The second mother showed appreciation of the open space available to the children in a village setting.

She went with both older daughters to her uncle's house in the village with her father. All night she threw up and soiled their bedding.

We took a trip to a friend's house that just had a son after seven daughters, and the house is big with a lot of open space, and my kids get spoiled there and [pointing at child with disability] she too. They have been our friend for a long time and really have been good to us.

In conclusion, each woman interviewed, irrespective of having a child with disability, performed daily chores and provided care for her family and extended family. Hence, daily routines and caring directly influenced the daily life experiences of these women with children with disabilities. These daily activities were clearly not seen as a burden. As one mother described it, “work is life, when we die work finishes.” As well, this domain reflects the mothers’ continued commitment toward their immediate families, their child with a disability, and their extended family living at home and away.

Theme 2: Daily Routines

The informants in this study did not express negative feelings toward their workload, which was heavy and ongoing. Every woman in Pakistani culture, regardless of her economic class or social status, performs household chores. In the upper classes women supervise the household chores, even if they do not physically perform them. What is unique to this study sample is that all participants reported performing routine caregiving functions associated with managing their household, such as cooking, cleaning, washing, and so forth. Some mothers reported that they had never kept a housemaid, and therefore started their day very early to get on with their daily routine. The following narrative describes a mother’s typical day:

I do have all the responsibility of the household and I do it all by myself. I don’t have any housemaid to help me. In the morning I get up, offer my prayers, then I read some Holy Koran and I start cooking breakfast for the family. That finishes by 8 o’clock and after that household chores begins such as cleaning, washing clothes and dishes...

I start cooking lunch at noon and by 1:30 children return from schools. I offer food to the children, then it is time to offer prayers, and more house chores, clearing off, dishwashing. I do not get time to take a nap. In the evening the children go to *masjid* and I do more chores.

Another mother reported a similar daily schedule and provided evidence by showing her hands, which were rough and calloused. She stated:

I do all the chores myself. Look here, how have my hands turned out doing all this work? I have to do it myself. Who will come to help? Today I have to wash clothes.

Mothers may get help when their children are at home. Often children were not asked to help, as they go to school in the morning and after school they play, do homework, or watch TV. Culturally, gender and age group define people's roles. Pakistani mothers operate with the basic understanding that household chores are their responsibility. One mother also mentioned her limited choices regarding the workload, stating, "obviously I have to do chores, as it is needed whether I like it or not."

In relation to logistical issues, it was evident from the interviews that laundry was a big, recurring chore that was often done by hand. Clean, running water is only dispensed for a short time in the early hours of the morning, which means that the women must begin their washing days early enough to utilize water at this time. The houses are designed in such a way that places to wash clothes are located outdoors with small water storage tanks located on the roofs. The stored water is used all day for activities such as cooking, mopping, and washing. During the winter months,

washing clothes with cold water in the open becomes very laborious and burdensome.

One of the mothers described her experience of washing for a household of seven members in these words:

It is so cold [during the month of December] and I washed clothes in the morning, now I am tired. Standing outside and washing clothes with cold water is very hard although I heated some water, which I used, but other water was very cold. I wash clothes every second day. I do not let them pile up, that's why I wash a couple of suits belonging to everyone every second day, otherwise it becomes very difficult to wash a pile after a week. I wash the clothes myself. I don't ask the children to help.

In this study, the caregivers were not concerned about the competing demands of caregiving functions and daily work, but instead mentioned the logistical problems of performing their household chores. Another theme that arose revolved around their health status.

Theme 3: Health

The health theme refers to the mothers' own health and well-being. The respondents invariably brought up the issue of their own health and wanted to converse freely about their physical condition. This illustrates that their caring responsibilities had an impact on these women physically as well as emotionally. The typical symptoms of poor health are lack of energy and motivation, which affects performance of work and caregiving because their work becomes more difficult and tedious. In Chapter 2 literature was presented that described the often-vulnerable health status of women in Pakistan. The cultural aspects of women's health issues were widespread throughout this sample. Nine of the eleven women

gave in-depth descriptions of their health problems without any leading inquiries.

The following narratives give some idea of the health problems faced by the informants:

Now I have passed the worse time, and now my bones have given me an ultimatum. Now I am very sick, all this is because I have been doing so much for so long for them.

I have pain in my breast. It has been a problem for four or five years. At that time a bump appeared here, then it had pus, which oozed out of it. They [her breasts] became so swollen and weighty that I had to support them with my arm. Then it developed into a wound, became a blister, and then busted. I did not take medicine, now it has a burning sensation. Obviously, when you ignore it—it will become cancer.

The mothers were constantly worried that if they fell sick or were experiencing any pain they would not be able to fulfill the demands of their role. Even when they were not well, they still performed the daily tasks of providing for their families:

I am sick—I have to do [household chores]. A mother cannot see children hungry at the time of meal, even if she is sick. Even if I do not have strength, I still do things for my children.

To summarize: health problems were diverse in this sample, and mothers were concerned because those problems hindered them in their caring responsibilities and daily activities. They seldom visited the doctor, and having health problems did not decrease their household chores.

Theme 4: *Pir* / *faqeer* (faith healer)

In Pakistan, families are considered fortunate to have a disabled child and children with disabilities are considered lucky because there is a belief that the child may be a *pir* or *faqeer* (faith healer):

It is not that he has a smaller brain, this is not the reason, only that in his extended family there's always someone like him. His dad's grandfather was like him. He looked fine but like Taqi he used to be sick. Then his uncle was the same. You wonder what will happen to him, he will become a *faqeer* there is nothing wrong about it.

Another mother gave an example of how her son was capable of getting his wishes granted by saying a prayer to Allah:

For example when he does not feel like going to school he prays to Allah: "Allah, please don't let the bus show up today." We dress him up and take him downstairs and wait for the school bus, but the bus does not come that day.

It is a very common belief that the prayers of children with disabilities are heard by Allah and for that reason many people come to such children to get their wishes granted. That their child was heard by Allah gave mothers pride in their children and established the closeness of the child to Allah. This narrative described another scenario where people get benefits because of this capability:

People come to him so he can pray for them. They ask him to pray to Allah to give them a son. He prayed and his prayers were heard.

This belief in *pir* and *faqeer* is prevalent in Indo-Pakistani culture, and therefore many people visit shrines and *pirs* as evidence of their religious beliefs. This matter will be further discussed in Chapter 5.

Theme 5: Social Support

The last theme of cultural realities focuses on social support from husbands, neighbors, and extended families. In Pakistani culture, the institution of marriage is not only strongly intact but is also a strong cultural norm, which makes the spousal relationship an essential aspect of this theme and one that demystifies the role and status of a wife. In terms of support, the respondents explained the dynamics between partners in various ways. Interactions with **neighbors** and **extended families** are built-in informal support systems, which come together to strengthen, magnify, and perpetuate social systems.

Spousal Relationship

National statistics show that more than 97% of Pakistani women get married (PARD, 1997). Marriage and family are very important in this culture. A woman's husband is her provider and protector and heads the family unit (Rouf, 1977). A woman's relationship with her husband becomes a significant factor in the state of the marriage (more so than in the West, where divorce is more of an option). The following are some quotes from mothers who did not enjoy support from their spouses.

The first mother lived with her two married brothers and her mother. She blamed her husband for not having any interest in their child with a disability and for not doing enough to cure the child's situation.

He has no interest, I look after the children myself. He never had any interest in children. Yes, the kids are his but he does not take any interest in them...

Actually their Abbu has not done this, never done this. It has been thirty years since the birth of Atif, in thirty years you see, he has never, not one day, ...given [the child a] shower, or cleaned him or changed his clothes or even looked after him.

Conversely, the next mother was appreciative of her husband for working so hard to support her family. Notice her concern for her husband when she describes his work and health:

Their *abbu* is trying to provide for their food, he goes out in the morning and returns in the evening. He comes after *aftari*[a meal at dusk]. Before Ramadan [month of fasting] he used to come for lunch. He cannot do his own work when he is at home, we also don't want him to do anything when he is home. He is quite old too. Fifty is old age, he looks much older than that and is very weak too.

Other mothers talked about the various ways in which husbands supported them, such as working two jobs, doing household chores, and sharing responsibility for the child in the mother's presence and in her absence, when she made visits to a village. The following narratives give the sense of spousal support these mothers feel:

He does all the groceries from the market. No, he does not help at home... Yes, he works two jobs to support us.

We have a very loving relationship and he cooperates with me. I leave all my house responsibilities and come to the school with these children, there are times when I have left his personal work undone, but he has never said a word about my share of work. He encourages me in taking better care of the children. In fact, he is always looking for ways that can ease my work. He is very supportive.

Data reveal that some respondents enjoyed good relationships with their husbands while others were not as fortunate. However, in the latter case the mothers were still recognized for their dedication to the role of wife and mother.

Neighbors

Neighbors are the second aspect of social support. Neighbors have close relationships in Pakistani culture because of their close proximity. They are called when help is needed, and often their children play together in the neighborhood. The mothers noted many types of behaviors from neighbors, a few negative and others positive. First, the negative behaviors that mothers witnessed involved neighborhood children mistreating of their child: "Children tease him."

Another mother did not like the pity she received from her neighbors, for her or her three children with disabilities. She preferred that her children went outside freely, so they could learn the way to their house and help her with errands, but:

...میں نے اپنے بچوں کو باہر لے جاتا ہوں، لیکن وہ لوگ ان کو دیکھ کر ہنس دیتے ہیں۔
 We cannot send them outside because people pity them. Still, I take them to the shops...if people cooperate then it is very beneficial, but when these children go out, people stop their work and start staring at them. This is very painful for me and I have never experienced such sentiments before.
 جب بچے باہر نکلتے ہیں تو لوگ ان کو دیکھ کر ہنس دیتے ہیں۔

This dimension of social support produced mixed, but mostly positive, responses. Most of the mothers reported neighbors caring for their child and informing them about the child's activities when the child got out or wandered away from home.

...میں نے اپنے بچوں کو باہر لے جاتا ہوں، لیکن وہ لوگ ان کو دیکھ کر ہنس دیتے ہیں۔
 He gets out [of the home] and they [the neighbors] come inform me that my child is going in that direction.
 جب بچے باہر نکلتے ہیں تو لوگ ان کو دیکھ کر ہنس دیتے ہیں۔

Another mother was comfortable with her daughter going out and playing in the neighborhood and then going to a neighbor's house to read the Koran. She stated:

The neighbors were good and look after her interests. She goes to learn Holy Koran from three girls in the neighborhood.

This mother compared her hometown's unpleasant attitude toward her disabled child—they “point out that something was wrong with this child”—with the more accepting attitude of “people encouraging him where he goes” in her new community of Islamabad. Back home, “they make comparisons with other children, which people in Islamabad do not do.” However, other mothers who lived in small towns or villages reported attitudes of acceptance toward their child with a disability: “Every one cares for her and loves her. When we go to the village...she goes and disappears in different homes.” Here the data diverge to both extremes. There was no relation to education or size of the city; sometimes in a village disability was accepted whereas in Islamabad children with disabilities were teased.

Extended Families

The final aspect of social support identified interaction with extended families. This is a major component of social support, especially in the absence of formal networks. Family is the most common grouping of people in Pakistani culture, and imperative contributions to the daily life experiences of mothers were evident in this aspect of social support. The majority of these mothers had good support networks. Social support has two components: formal (financial and community resources) and informal (emotional and social). Formal support is almost non-existent in Pakistan; however, informal support is evident and plentiful, and in

these cases extended to financial support. One reason for strong support and involvement was that the majority of couples are related, often being first cousins to each other. In a society where formal support systems are absent, relationships become important linkages and regulator of norms. The social support these mothers received from their extended families is illustrated in the following quotes:

My sister, nephew and all ...All—I even say my neighbors too support me.

My sister lives next door. I call her over if I need something done.

My family takes extra care. Family treats me very well. They [her in-laws] are very nice and they say I am kind and good and I say they are kind.

Amma, 38 years old, married, 3 children, 10 years in the village, 10 years in the city.

The majority of these families had very strong link with members of their extended family and made frequent visits to the villages where these members live. The following narratives convey how children who have been urbanized and educated in professional schools have different values concerning space and people than their rural counterparts:

Amma, 38 years old, married, 3 children, 10 years in the village, 10 years in the city.

We cannot adjust there because from the beginning we have been living separately. Secondly, here *Ammi* [mom] and *Abbu* [dad] are ours and there they do not belong to us—they go to different places, leaving us by ourselves, all the time. They go with relatives and we feel ignored. That's why we could not adjust there. Here *Abbu* and *Ammi* give all their time to us. Over there the surroundings are different. We lived in one house...

They continued to explain the distance created between them and their parents in the village setting:

Here we have a whole house all to ourselves. It happens that *Abbu* goes to the office and then he is at home, then we have him with us for the whole evening. At dinnertime we all talk and tell about our day—there it was not

possible. There when Abbu came home, he obviously first went to grandmother and he spends most of his time with relatives.

The mother of these children elaborated on the problems she faced due to her children's education:

The house is big and every family has two three rooms but still it is one house. When [the children] have exams, guests come--they show no consideration that children were having exams. What anyone feels like they did, such as listening to loud music. When my children could not study they use to cry and beg me to do something. When I told some relative, they said, "we cannot stop living because of your children."

From the preceding one gets a sense of the tensions involved in living in a house that has many family members, even though this house was divided into different sections for the different families. In the following passage, another mother describes her way of life when she is with her extended family:

When I am there [the village] guests call on me constantly—I sit with them for hours, then I take off with them to visit someone else. [The children] used to follow me around asking me how long will I take to get back. They fuss—why do you come here? They complain—she is no more ours and Abbu is not ours anymore he sits with other people and relatives outside [in the male part of the house] and does not sit with us.

These ethnographic data depict these families as very involved with their extended families that live elsewhere. The educated children in this sample seem to have distanced themselves from the extended families and villages, while their parents still made frequent visits to those families. Parents particularly liked the open space and family support they found when they visited; however, the educated children did not like the communal living it involved.

Close relationships with extended family also encourage intermarriage. There were eight couples in this study who were married to their first or second cousins.

The following illustrates these intertwined marriages:

Rouf's sisters were here and many other relatives. The older daughter-in-law is my brother's daughter. And Shafeeq-ul-Rehman's [the second son] wife is my sister's daughter. And the one in my brother's house is Rouf's sister meaning my brother and Rouf's sister are married. [Only] Aysha and Nafees went outside, all others were married within the family.

In conclusion, the cultural realities consisted of five themes: caring, with many dimensions; daily routine; health, *pir/faqueer*; and social support. These were all very much part of the context in which mothers experienced their daily lives. These themes overlapped, and influenced and strengthened each other. The mothers, not aware of any other context, were comfortable within the parameters of their culture and religion and used the above themes to derive benefit on many levels.

Chapter 5

ANALYSIS

The results of analysis indicate that the women interviewed encompassed a broad spectrum of values, beliefs, and practices. As with all ethnographic studies, the experiences presented here do not completely represent the totality of the reality of the women interviewed. It is impossible to reconstruct through analysis the exact experiences or state of mind of another person (Rose & Webb, 1998), and each researcher brings to the interpretation of the material his or her own biases, values, and experiences (Sandelowski, 1993). Three major domains emerged from the analysis of narratives of the daily life experiences of mothers in this study.

- 1. Religious Beliefs**
- 2. Intrapersonal**
- 3. Cultural Realities**

ACCEPTANCE AND CONTINUED COMMITMENT TO CARE

The major phenomena that strongly emerged throughout the sample were that of acceptance of a child's disability and continuous commitment to care. Mothers and their families, regardless of their socioeconomic status, extended family support, or any other factor or combination of factors, accepted the disability of their child. They were devoted and committed to the care of the child, with support from spouses and extended families and in spite of the constraints placed on them by societal values, and limited opportunities for personal growth. This analysis offers a holistic

view of the context (Agar, 1986) and the aspects of daily life for mothers who provided care for children with disabilities in Islamabad, Pakistan.

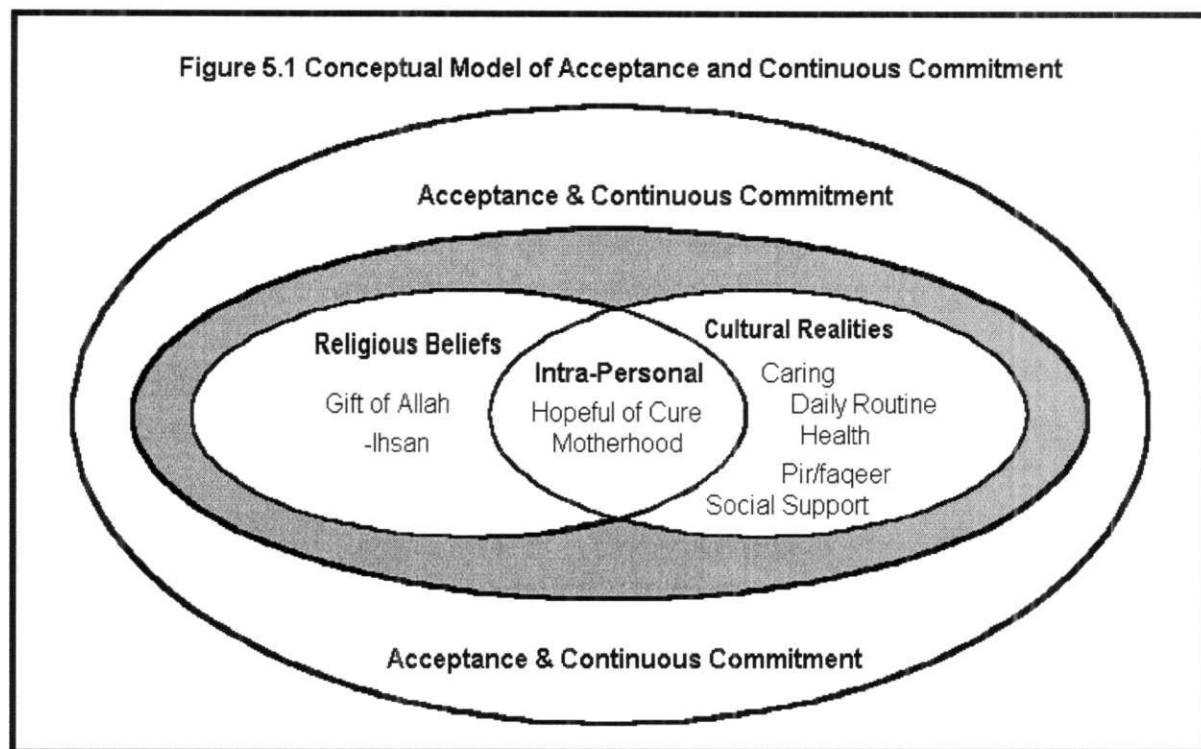


Figure 5.1 illustrates a conceptual model of the overarching phenomena of acceptance and continuous commitment. The religious and the cultural realities domains overlap with the area in the middle, which represents the intrapersonal domain. In the religious domain one powerful theme, *gift of Allah*, was identified. In the intrapersonal domain two themes, *hopeful of cure* and *motherhood*, emerged from the narratives of the mothers' interviews. This domain reflects the internal influences on mothers of religious beliefs and cultural realities. The gray area in Figure 5.1 signifies the context of these mothers, which may have many domains; this study focused on three; religious, intrapersonal and cultural realities. Five themes were identified in the cultural realities domain: *caring*, *daily routine*, *health*,

pir/faqueer, and *social support*. In this conceptual model, these three interactive domains together resulted in mothers' acceptance of their children's disabilities and continuous commitment to their care.

The emerging themes offered participants' emic view of the phenomena of acceptance and continued commitment to care. The following text concerning the three major domains and their themes has been presented in a multivocal way, in an attempt to have the informants themselves speak, to tell their own stories of their experiences in caring for a child with disability in their own way (Denzin, 1994).

1 RELIGIOUS BELIEF DOMAIN

The religious domain with its one theme, gift of Allah, gave the mothers strength to accept the disability in their child's life and promoted their continuous commitment to care for their child. Within Islamic society, even when religious beliefs are not practiced, religious values and language permeate everyday life. Muslims believe in the patient acceptance of one's fate, however unpleasant it may be. This attitude toward life has sometimes been referred to as fatalist (Miles 1988; Rouf, 1977).

It is worth clarifying the distinction between religion and ethno-religious traditions. Religion is considered as those practices outlined by the Koran and Hadith. By contrast, ethno-religious traditions in the context of this study are defined as those beliefs and practices that are based on hearsay, or common transgenerational perceptions or are culturally embedded. The language used to describe some practices may be religiously based although in fact there is no religious belief that

forms the basis for those practices. Such practices provide grounding to the mothers, giving strength and the ability to cope with disabilities.

Theme I: Gift of Allah Theme

In Muslim societies, all disabilities and abilities are perceived to be “by the will of Allah” (Al-Krenawi & Graham, 1999b; Dipojono, 1972; Miles, 1990). The cornerstone of Islamic ideology is that all things that happen to a person, good or bad, are the will of Allah (Hashmi, 2000). Muslims therefore accept their fate with strong faith and great patience (Al-Krenawi & Graham, 1999b). These two religious beliefs—will of Allah and acceptance of fate—affect the mothers’ outlook and perceptions of their children’s disabilities. In particular, a child with a disability is perceived as a gift of Allah.

The mothers in this study were situated in a social context that, like any other, is maintained with a set of complex beliefs. The first is that Allah has given them the ability to provide care to a child with disability. Second, these parents are performing a service to Allah because it is He who enlists them to provide for those with disabilities. Third, these parents are tested by the disability of their child, which leads to the fourth belief, that gratitude is due to Allah for their child with a disability. Finally, the parents are promised rewards, both tangible and intangible, for their caring responsibilities. These beliefs transform the child with a disability into a gift of Allah. This perception facilitates the acceptance of the child despite his or her demanding needs for care, which are draining, physically and emotionally.

The finding gift of Allah, was not unique to this study. Badr-e- Haram and Edwin (1982) found that uneducated families tended to characterize their disabled

child as “given by Allah,” “*Allah wala* [belong],” or “*Allah's log* [people]”. These authors state that educated parents are most likely to use terms equivalent to “mental retardation,” “mental problem,” and “mental slowness.” This finding was consistent with the stance suggested by Al-Krenawi (1996) and Al-Krenawi and Graham (1996) that, according to Arab beliefs, mental illness is a result of the interaction between human beings and evil spirits, and was God given.

The five beliefs that mothers illustrated in their narratives—*ability given, services to, test by, thankful to Allah, and rewards*—are all found in the Koran.

Confirmation of these beliefs can be found in the following quotes from that source:

- “Allah does not lay a responsibility on anyone beyond his capacity”(Ansari, I, p. 226).
- “It is Him that you serve” (Ansari I, p. 153).
- “Thus we have made some of them a means for testing others” (Ansari, II, p. 236).
- “Give thanks to Allah” (Ansari I, 1988, 153).
- “The wrongs were always ascribed to the will of Allah. By hope, prayers and only by the will of Allah were the solutions to be found. For irreversible wrongs [e.g. disabilities or chronic illnesses] the struggle was life long and Allah promised rewards (Ansari II, 1988, 40).

Divergence in ethno-religious traditions and religion is a commonly observable fact in this sample. Ethno-religious traditions are diverse in different people at different times and in different situations (Stowasser, 1998; Mernissi, 1991). In fact, they are shaped according to local cultural and societal values. With such a strong religious underpinning to their special status, one might assume that all children with disabilities are looked after and secure. To the contrary, children are also abused and neglected. There is tension within the ethno-religious traditions, as not everyone shares the same beliefs. These diverse beliefs were expressed in many

different ways. For example, the next theme, *hopeful of cure*, encompassed a variety of practices mothers adopted to find cures for their children with disabilities.

In this sample, the overarching phenomenon of acceptance of the child's disability is understood in the context of religious beliefs and the limited opportunities within their cultural setting, which does not provide services to women and children. This narrative points to their most provocative realities:

Thanks, Allah even if he is not normal—you don't throw your child out, he is my jageer ki boti [my precious part], how can I throw him out?

Another point of interest is that the mothers did not view themselves as responsible for bearing a child with disability, because they don't have any control: all things, good and bad, happen by the will of Allah. Although disabilities add to their responsibilities, the belief is that they become a "chosen one" and therefore have to "strive harder" to be worthy of the promised intangible rewards.

In summary, *gift of Allah* is perceived by the mothers interviewed to be rooted in Koranic teaching and therefore very religious in nature. For this reason alone, the mothers in this study would not conceive of saying or thinking otherwise. Not only is the child a gift of Allah, but also there are some promised rewards for caring. These religious underpinnings have a strong influence on these mothers and contribute to their acceptance of the disability (Ansari II, 1988, 40, 93). The following discussion of *ihsan* clarifies the concept of promised intangible rewards. *Ihsan* also strengthens their belief system and encourages them in their continuous commitment to care.

Concept of *Ihsan*. The concept of *ihsan* will be described in detail to provide an ideological underpinning to readers who are unfamiliar with this concept and the way it is manifested in this study. This concept has deep roots in Islamic teachings and is referred to in disability studies in Pakistan (Miles, 1995; Wadud, 1986). To understand the concept of *ihsan* one has to grasp the concept of *adl* (justice). Fyzee, a well-known scholar of Islam, defined *adl* as “to be equal, neither more nor less” (1978, p.17). For example, in the court of justice the claims of two parties must be considered evenly without undue emphasis on either side. Western societies give concrete form to this balance in the image of scales that must be even. The Koran puts great emphasis on the right to seek justice and the duty to do justice.

Allah has promised perfect *adl* to humans. The Koran clearly states that “judgment lies with Allah alone...He is the best Judge” and “Indeed Allah wrongs none, not even as much as an atom’s weight”(Ansari II, 1988, 237, 39). Part of *adl* is *ihsan*, which recognizes individual merit. Merit is not determined by lineage or worldly success, but of right beliefs and just action. Furthermore, it distinguishes between passive believers and those who strive hard in the cause of Allah. Although Allah has promised good to all believers, those who strive harder are exalted above the passive ones (Ansari II, 1988, 72). In the working of *adl*, individual merit is taken into consideration with respect to reward and punishment. For example, the deeds of a rich man who gives a lot to charity, as compared to a poor man who gives a little to charity, would be considered in relation to their financial background.

The concept of *ihsan* has two meanings in Islamic ideology, and both provide reasons for the mothers' stance of acceptance of the disability. According to Fyzee, *ihsan* literally means "restoring the balance by making up a loss or deficiency" (1978, p. 17). In order to understand this concept, it is important to grasp the nature of the ideal society or community (*ummah*) as perceived by Islam. The word "*ummah*" come from the root "umm" or "mother." The ideal of *ummah* cares about all its members just as an ideal mother cares equally about all her children, while keeping their different needs in mind. For example, the mothers interviewed gave a lot more, physically and emotionally, to their children with disabilities than they did to their other children. This act of giving more to one child may seem to violate the principles of *adl*. Nevertheless, it exemplifies the spirit of *ihsan* by helping to compensate for the deficiency of a child who is unable without aid to meet the requirements of life. Thus, in a society, *ihsan* extends to cases when other members of a society support an individual who faces trials, financial, physical, or emotional, in spite of his or her best efforts. This support restores to equilibrium the disturbed balance of the society (Hussain, 2001). Welfare systems are a good example of how *ihsan* is operationalized in Western society.

The second meaning of *ihsan* clarifies the concept of promised rewards in the *gift of Allah* theme. In this particular meaning *Ihsan* is an alien concept to the West. *Ihsan* signifies good acts or thoughts that arise out of a strong love of Allah and lead to a closer relationship with Him. "Submit to divine commandments and persevere in doing good....Allah loves those who do good" (Ansari II, p. 192). Applying this to

the mothers of this study, we see that their caregiving behavior is considered a good act that reflects their love for Allah. In return, Allah loves them and rewards them (Ansari II, 1988, 118). Therefore, caring offers rewards that are both tangible and intangible. Tangible rewards refer to worldly gains such as social standing, and the status of a mother and caregiver, and intangible rewards refer to increased intimacy with Allah, as well as other intangible rewards such as a place in paradise.

How does this study's sample differ from mothers who are raising normal children? It is different for the mothers of disabled children because they believe they are "chosen" for the extra caring responsibilities that are required in caring for a child with disabilities. Being a chosen one gives them a chance to "exalt above" mothers of normal children because they have to "strive harder." Like the example of the charity given by two people of different financial backgrounds, caring responsibilities are taken into consideration in the process of *adl*. The two aspects of the concept of *ihsan* are central because, first, the mothers' caring balances the society in compensating for deficiency and, second, they "persevere in doing good," which reflects their close relationship with Allah, leading to tangible and intangible rewards.

Mothers would not know the literal meaning or the definition of *ihsan*; however, the concept is pervasive in Pakistani society and is practiced on a daily basis. Providing care and food to members of extended families, looking after a family member, offering food to a *faqeer*, teaching the Koran, and giving servant quarters to a family that has a child with disability are some of the many daily acts

that fall within this same principle. There are also people who do not care about *ihsan*. This contradiction will be elaborated in the following section.

To summarize this domain: a thorough examination of the literature would lead one to assume that, although the study setting was less urban in nature than the setting's explored in the research, the concept of burden would be manifest. To the contrary, in this sample the social construct that emerged was "*gift of Allah*," explicated and supported by the religious beliefs of the mothers. Attendant on these religious beliefs was acceptance of children with disabilities and commitment to their care. None of the mothers showed any resentment toward Allah for giving them a child with disability, and none felt guilty or were blamed by their spouses for bearing a child with disabilities. The mothers' religious beliefs were a very strong predictor for acceptance and continuous commitment to care. Both aspects of *ihsan* influenced the mothers: they were doing good in caring for their disabled children to achieve closeness to Allah and rewards. Therefore, they did not perceive care as burden.

2. INTRAPERSONAL DOMAIN

The intrapersonal domain represents the spiritual aspects of the mothers in this study. This domain overlaps with the religious beliefs and cultural realities domains. Two themes underlie this domain: *hopeful of cure* and *motherhood*. Every mother was hopeful of a cure for the disability and used various healing methods in an attempt to attain normality. The theme of *motherhood* had four aspects: being a mother, good mother, social approval, and no blame for bearing a child with disability. The following section discusses the meaning of the two themes of the intrapersonal domain.

Theme 1: Hopeful of cure

The mothers were constantly and vigorously engaged in a number of activities that they hoped would lead to a cure for disability, and this hope supported their acceptance of the disability. Maintaining hope of finding a cure and believing that their child is a gift of Allah are very effective coping strategies that also contribute to acceptance of their child's disability and the motivation to continuously commit to care. Hope also provides motivation because finding a cure would relieve them of constant worry about dependency issues and the need to cope with a situation that can shadow their whole life. The hope for a cure and the belief that the child is a gift gives these mothers some control over their life, and this gives them strength to cope with the disability.

On a societal level there is a parallel process that illustrates the conflicting beliefs regarding disability. First, Pakistanis view mothers of children with

disabilities as “fortunate” and children with disabilities as “lucky.” This societal belief supports mothers’ acceptance of the disability. Conversely, these same individuals will give parents suggestions and advice about where to take the child in the search for a cure. Hence, there is simultaneously, social acceptance of disabilities and support for parents searching for a cure. This tension between acceptance and non-acceptance manifested by the search for a cure is evident on an individual as well as a collective level.

The approach is not a fatalist one; women have prerogatives under the ethnoreligious traditions. They do not simply accept disabilities and take no further action to improve the condition. It is clear that acceptance and continued commitment to care go hand in hand. The mothers of this study first asked, what is this? The next question they asked was, what do we do to make it better? To answer the first question requires them to familiarize themselves with the symptoms and conditions of the disability. The second spurs a vigorous search for a cure. Rather than being fatalist, this is an active, relentless pursuit that demonstrates a continuous commitment to care. This commitment to the elimination of the disability, in order to set their child free of both the disability and dependence on others, is important to mothers and shows their deep commitment to the child and the motherhood role. The pathways they take in the pursuit of a cure, along with the reasons for the mothers’ choices, are discussed in the following section.

Interventions. In the process of hoping for a cure, three healing systems—allopathic, homeopathic, and faith—were utilized. Most mothers in the study

employed the latter two, although some used all three systems, and one family utilized only allopathic and faith healing.

It was clear that the mothers in this study had preferences that were influenced by their experience of the manner in which healing services were delivered. Allopathic medicine is the art and science of diagnosis and treatment of disease with the aid of laboratory tests and drugs (Winkwist & Akhtar, 1997). Homeopathic remedies are extremely diluted solutions (usually one part per million or less) of assorted herbs, animal products, and chemicals (Homeopathy, online). The portions are so minute that they do not show up in laboratory tests. The efficacy of homeopathic “medicines” is currently unknown. Because of the low levels of medicine in these mixtures, it appears that faith in the treatment process is required to make homeopathy effective. Faith healing refers to the practice of going to faith healers in the search for a cure. Faith healers use verses from the Koran, to be worn in a *taveez* (amulet), and use water in their rituals (Al-Krenawi & Graham, 1999b; Kinzie, Teoh, & Tan, 1976; Pfleiderer, 1988).

The literature uses different terms for faith healing such as “traditional healing systems” (Al-Krenawi & Graham, 1999, 2000), “folk remedies,” (Barsh, 1997), “ritual healing” (Bourguignon & Howard, 1998) “supernatural help” (Fairclough, 1995), “ethnopsychiatry” (Kinzie et al., 1976), “religious healing systems” (Al-Krenawi & Graham, 1996; Al-Krenawi et al., 2000; Mernissi, 1996; Unisa, Somayajulu, Das, Kumar, & Remachandran, 1990; Winkwist & Akhtar, 1997), “oriental medicine” (Cho, 2000), and “informal healthcare” (Turner & Cherrin, 1998). These studies are consistent in indicating that primarily women

utilize faith healing, which is religious in nature, and that the relationships between these women and the faith healers can be best described as a helping alliance. A relationship of this nature provides women with an equal footing that offers a dramatic contrast to their subordinate position in a patriarchal society (Al-Krenawi et al., 2000; Mernissi, 1996).

In the present study, families' continual pursuit of care is evident from the utilization of faith healing practices. Mothers stated, "Mostly I do homeopathic medicine," and some "have given up on [medical] treatment." Another mother was not utilizing allopathic medicine as "my children cannot handle prescription medicines." This mother questioned the logic behind allopathic treatment:

We gave those medicines, well the medicine they gave were Valium and Diazepam. That was it, to give half a tablet, half a tablet, I said what is this, this an addiction, not a treatment...this will keep her sleepy.

This mother thought that such treatment was not helpful in that it was not a pathway to cure. The mothers' narratives highlighted disenchantment with the allopathic healing system (pointed out in Chapter 4). There are three reasons these mothers emphasized faith healing practices in this sample: The mothers found hope, accessibility, and cost-effectiveness. The reason allopathic medicine is less accessed is that the facilities are not equipped with the advanced technology and specific services (e.g., speech therapist, physical therapist) that are needed for disability reduction and maintenance. Due to high caseloads, and class and education differentials, doctors could not strike up a therapeutic alliance with the mothers of

children with disabilities, who in this sample belonged to lower classes and had very little education, if any. In addition, whatever services were available were costly.

Literature also provides some insight in the practices of faith healing. A few studies in the literature have highlighted some of the differences between faith healing practices and allopathic treatment (Al-Krenawi & Graham, 1999; Barsh, 1997; Mernissi, 1996). These differences were similar to those focused in the current study and offer some explanation for why allopathic practice appeared to be out of favor with this study's informants. First and foremost, the allopathic approach does not provide any hope to the mothers, and typically responds to the disability with drugs (Barsh, 1997) to "successfully address physical symptoms" (Al-Krenawi & Graham, 1999b, p. 219). Moreover, there are very few trained professionals in the field of disabilities in government hospitals, where the parents of this study received services (Miles, 1989). One of the most common allopathic treatments, as pointed out by one mother, is to give sedatives to calm the child down. In addition, this approach is expensive as compared to other modalities, as it requires laboratory, and radiology investigations and costly medicines (Winkwist & Akhtar, 1997). Furthermore, hospitals are formal places of business where the mothers of children with disabilities hold a powerless position and the doctor is the expert. In the diagnostic process, a mother cannot provide the precise, technical information that a doctor needs, but can only talk in an awkward, colloquial Urdu or her provincial language that she is used to speaking at home. With doctors she has to pay the fee—a fixed amount—before she can even enter the doctor's office, regardless of the outcome of the interventions (Mernissi, 1996).

By contrast, faith healing methods do not require expensive investigations, and medicines are included in the minimal consultation fee. In addition, this method acknowledges the individuality of the patient's physiology and employs complicated and individualized treatments. Healers engage themselves in innovation, experimentation, and exchange of experiences with patients (Barsh, 1997). They "struck a stronger therapeutic alliance, tended to diagnose more comprehensively, and were perceived by many patients as being more clinically beneficial" (Al-Krenawi, 1999b, p. 219). As compared to hospitals, in shrines troubled mothers can directly access the source of the cure. Mothers can sit or stand as they please, describe what ails them, make a diagnosis, suggest a solution or solutions that suit their situation, and explain to the *pir* (buried saint or *faqueer* on the premises) what they prefer and the reasons for that preference. Mothers speak the language they are comfortable with, in the tone and measure they believe appropriately represents their situation and mood. In shrines, mothers decide what gift or sacrifice to offer once their wish is realized—not before (Mernissi, 1996).

Two Pakistani studies conducted by Winkvist and Akhtar (1997) and Schmidt (1983) found the same trend in the utilization of healing systems in the provinces of Punjab and the North West Frontier Province (NWFP) as noted here. The current study found that (1) mothers' utilization of different healing systems shows flexibility; (2) mothers were cost-conscious; (3) they used the system that offered a higher level of confidence in the health worker, which was directly associated with social position and alliance between healers and mothers; (4) the delivery of services for allopathic systems and those for faith healing systems are

very different. The mothers found faith healing more suitable because it provided them with hope for a cure. The more hopeful they were of finding a cure, the more they accepted the child's disability and were committed to finding a cure. Success in finding a cure through faith healing is not uncommon in the literature. People with staunch religious beliefs consider divine intervention a part of the healing process (Al-Krenawi & Graham, 1999b). Case histories of mentally retarded children who were "cured" by Koranic remedies have been presented by El-Jilani (1978) in Pakistan, in England by Sembhi & Dein (1998), and in Jordan by Al-Krenawi et al. (2000). In Haiti, faith healers are very effective in eliminating the symptoms of people with deformities (Bourguignon & Howard, 1998). The next section presents the *sawali* role that the mothers of this study take in the pursuit of cure.

The role of *sawali* (supplicant) is a common one adopted by people in the Indo-Pakistan subcontinent, as it provides them with hope and the strength to cope. An Indian study surveyed five religious places of Christians, Hindus and Muslims in India and presented a profile of a *sawali*. The research found *sawalis* are drawn from all ages, socioeconomic classes, educational levels, and occupational categories. They make frequent visits to shrines. Although the majority of *sawalis* are adherents of the same religion as the place of worship, a significantly large number are from different religions. The purpose of visits for all *sawalis*, regardless of religious belief systems, is primarily spiritual, and secondarily for personal reasons. People without education visit for spiritual reasons, whereas most visitors with a university education come for personal reasons (Unisa et al., 1990). One spiritual reason is a mental illness that is believed to have occurred as a result of an interaction of human

and evil spirits (Al-Krenawi & Graham, 1999b). Personal reasons may involve making a wish for a male child or other marital issues (Winkvist & Akhtar, 1997). This study illuminates the widespread utilization of faith healing practices and the role people adopt to meet their needs and wishes.

The *sawali* mothers are very vulnerable because of their desperate attempt to find a cure. In the role of a *sawali*, they are very powerless and needy. They follow people's suggestions and travel to places in pursuit of a remedy for their child. *Sawalis* visit shrines and *pir* to make their wishes come true. Pfleiderer (1988) reported that many *sawalis* brought their mentally ill relatives (*pagal log*) to visit one of the many shrines in the Indo-Pakistan subcontinent. Relatives "often bring them in chains to prevent violent acts or to keep them from running away. They were tied to the a pillar in one of the patient's quarters" (p.419). This study indicates that shrines are specially constructed with the provision of patients' quarters. The mothers of this study visited shrines on a regular basis, making desperate attempts to find a cure for their own children with disabilities and to make offerings. This was, as one father said, a "family hobby" and hence carries some intrapersonal benefits that kept the parents going to the shrines and *faqeers*.

Theme 2: Motherhood

Patriarchal societies maintain men's leadership and authority over the household, the economy, and politics (Al-Krenawi, 1996). This puts women at a structural disadvantage in society (Al-Krenawi & Graham, 1996; El-Saadawi, 1977, 1997). Therefore, women's social status is strongly correlated with being married and rearing children (El-Saadawi, 1977, 1997). In this study the theme of

motherhood consisted of four aspects: (1) being a mother, (2) good mother, (3) social approval, and (4) no blame. The motherhood theme highlights the perception of religious beliefs and cultural realities in relation to the mothers of this study. Many aspects of motherhood came forth that are intertwined, and hence are presented with little distinction among them.

First, **being a mother** is an important aspect of gaining social status. Motherhood encompasses more than childrearing techniques (Leonard, 1996). Wearing (1984) has compiled an image of motherhood obtained through the narratives of Western women. She found that women expect themselves to have children and to find purpose and fulfillment through them. "This is a women's privilege and duty. Although motherhood may be more difficult than expected...the rewards are worth the effort. There is an ideal of a 'good' mother towards which all mothers should strive" (Wearing, 1984, p. 42, 44, 49). Birns and Hay (1988) believe that the experience of motherhood is affected by theories and ideologies concerning women's experiences as mothers in the society at large.

The experience of motherhood changes with class and level of education; motherhood is important to all women regardless of class, educational level or culture. Motherhood played a significant role in the lives of the sample in this study. Children gave the women in this study a purpose as well as a source of fulfillment in life in the same way as the Wearing's (1984) study described children as a source of fulfillment for Western women. Societal dynamics promote the acceptance of certain roles for certain of its members through the application of certain beliefs. The Indian author Usha Nilsson (1991) discusses the ways society applies roles to its members.

She believes that “from early childhood, girls are programmed by family and society to follow certain scripts.” She describes scripts as an “ongoing program developed in early childhood under parental influence which directs the individual’s behavior in the most important aspects of life” (p.101). This script emphasizes the motherhood role as an element of self-fulfillment and applies just as strongly to Western women (Birn & Hay, 1988).

Cultural and religious pressures dictate that the women in this study **become mothers**. Religious and cultural beliefs influence the societal values that regulate the mothers’ role and responsibilities. Being a mother is considered to be an essential role for women in this group, whether it involved raising a disabled child (“thank Allah even if he is not normal”) or someone else’s children (“..my aunt’s daughter does not have children, she is raising two children of her sister-in-law..”). These mothers find fulfillment in children and their household (Kandiyoti, 1988; Nilsson, 1991; Wearing 1984). Cultural and religious expectations give women very little room to choose not to become a mother; in fact, they encourage them to accept and continuously commit to care as mothers.

Turner and Cherrin (1998) assert that in many Asian countries women are under constant pressure to produce children. The following narratives demonstrate the perceptions and attitudes regarding having children in this sample, and establish the importance of motherhood in their social order. In one statement a mother captures the essence of life without a child: “I have daughters, if I did not have them what would I have done?” While this mother would have been far happier to have sons, she was happy to have daughters because it meant she was a mother.

Motherhood is so important that a mother with three children who have disabilities stated, “Not to have children is obviously more painful.” Clearly, having a child with a disability was not considered as attractive as having normal children; nonetheless, she felt that having a child with a disability is better than not having child at all. The pain was evident in her tone as she elaborated: “one can hang on” to children with disabilities because they provide the role of motherhood, albeit with much sacrifice and hardship. To achieve the role of mother, this mother accepted the disability and the hardship—both mental and physical—associated with care.

In Pakistan, the rationale for marriage is having children (Haj, 1992; Hashmi, 2000; Jawad, 1998; Kandiyoti, 1988). The marriages of the women in this sample were arranged by their families and were not for love, as in the West (Turner & Cherrin, 1998). This process is considered a necessity in a culture where female children are viewed as a responsibility and financial liability for fathers. A female child is given in marriage to a man who can provide for her needs, and in return the female is expected to bear children for the man and his family and manage the household affairs (Vock, 1988). If women do not bear children they are perceived as not worthy, even of having their basic needs met (Harway & Liss, 1988; Winkvist & Akhtar, 1997). So what choice does this leave for women?

“Pakistan is a nation of patriarchs, arranged marriages, dutiful daughters and obedient wives” (Williams, 1999, p. 200). Kandiyoti (1988) believes that classic patriarchy exists in Pakistan, which is located in a “patriarchal belt” that includes North Africa, the Middle East, India, and China. Women are expected to maintain the household, bring up children, and cater to the needs of the men (Abu-Lughod,

1985). Women in Pakistan, as in most societies, value their role as mothers and wives. The fulfillment of that role, to the best of one's ability, may bring harmony and peace and a strong feeling of belonging to the family unit (Nilsson, 1991). The social value of the role of mother is determined by the society. Kandiyoti (1988) asserts that in patriarchy the association with a spouse and later, with male children gives the women social standing and financial security. In old age women gain even greater status because they are mothers of sons who become important males in the hierarchy (Haj, 1992). Childless women are perceived as worthless (Winkvist & Akhtar, 1997). For the sample of this study motherhood was the only role of significance, since they do not work outside the home, have limited personal resources, and experience constraints from their cultural and religious belief systems.

The second aspect of motherhood found in this study is that of being a **good mother**. All societies, whether primitive or advanced, assign certain roles to their members; in fact, this interlocking system of roles is the very structure of any society (Nilsson, 1991). Commitment and devotion to the role of mother earns social approval and respect from husbands, families, and neighbors. "My family respects me because I am a good mother," stated one mother. Some women are of the opinion that "I am a good mother, that's why Allah has blessed me with such a son." One mother believed she had "such a son"—a gift of Allah—because she is a good mother.

Raising children gives some control to women who become mothers. As one mother put it, "children are pride." Mothers get to nurture their children, educate them, and groom them, and they expect them to become productive members of

society. Of course, there are gains for parents if a child succeeds because both parents are often dependent on their children in old age (Haj, 1992). Partly for this reason, another mother who had three children with disabilities demonstrated that she feels empty in this life: “we did not get anything in this world.” She felt her life was meaningless because she “cannot enjoy food, clothes or anything because of [the children]” and has no hope of getting reciprocal care when she gets older. Harway and Liss (1988) attribute this strong attachment to children to the fact that these mothers do not have any control in other matters: “because of her lack of power and control in other areas of her life, when her children are born, the Muslim mother focuses all of her attention, emotions, and love on her children” (p. 113).

Women also get higher religious status from being a mother. In Islam, motherhood is the most cherished role for women, and it is believed that Allah grants women more respect and status for fulfilling their role as a mother than for any other (Hashmi, 2000; Rouf, 1977). The Hadith illustrates the religious underpinning that makes motherhood so essential for women and the intangible rewards associated with this role: A man asked Prophet Mohammed,

“Who deserves my service most after Allah?” The Prophet said, “Your mother.” The person asked again: “And who is next?” The Prophet said, “Your mother.” The man asked further, “And who is next?” The Prophet replied, “Your mother.” The man asked once more, “And who is next?” The Prophet, peace be upon him, said: “Your father.” (Rouf, 1977)

The third aspect of motherhood is the **social approval** these mothers received from their spouse, neighbors, and extended family. They performed household chores all day to meet the demands of caring, and this effort earned them recognition and appreciation from their community. The respondents indicated strong feelings of

competency as parents and caregivers that were supported when their husbands engaged in “comparing with sister-in-laws.” One mother stated, “people appreciate me for looking after my children. This is the thing—when people appreciate me for keeping the children so well I feel happy and peaceful.” This encouragement and appreciation enhanced their esteem and also gave them pride in their role. Through the successful fulfillment of their multiple roles of mother, wife, aunt, daughter, daughter-in-law, and sister-in-law they received social approval from those around them.

However, this social approval is not a fixed state, but a fluid one for which mothers have to renegotiate their social position in their families. First, they primarily gained value through their interactions with their husbands. As one mother stated, “he knows I am an obedient wife, I stay home and work all day.” Their extended family supported them because these mothers provided them with care, nurturing, and a place to live (detailed in the social support section below). These mothers were situated within a system that manages conformity, and within that system they were providing care and services to extended families members who reciprocated by extending social approval.

The final aspect of motherhood that influenced the mothers of this study was that they were **not blamed** for bearing a child with disability; rather the child was perceived as a “gift of Allah.” The concept of their child with disability as a gift of Allah meant a lot to these mothers, for the mothers were not seen as responsible for the disability and carried no blame.

The reason that the disability of the child was not blamed on the mother has religious roots. The notion of blaming women is not found in Islam. The Koranic story of creation is very different from that in the Bible. In the Islamic version Adam and Eve are depicted as equally responsible. In fact Adam apologized for both of them “Thereupon Adam learned from his Lord some words and repented, and his lord accepted his repentance, for he is Much Relenting, Most compassionate” (Ansari II, 1988, p. 65). In this example, Allah blames neither Eve nor Adam for their actions—a notion that is evident in Pakistani society. Not blaming the mothers for disability means that the fathers simply accept the child as given to them by Allah.

The religious image of motherhood enhances mothers’ social status, which impacts on cultural values and self-perception of the mothers in the current study. Al-Krenawi and Graham’s (1999b) research on Arabs discovered that “religion is central to Muslim self-perception” (p. 54), and therefore influences cultural realities and appears to be a factor of positive influence on mothers’ self-perception.

The mothers in the current study report feelings of high self-esteem, showing that strong religious beliefs correlate to an improved self-perception. Also relevant to this study is the relationship between social support and self-perceptions, as found in the literature (Affleck, Tennen, Howe, Roscher & Walker, 1989; Fondacaro & Moos, 1987; Seybold et al., 1991). Satisfaction with social support is related to a mother’s feeling of competence as a parent and her ability to balance multiple role demands (Seybold et al., 1991). One of the blessings of the mothers in this study is the strong social support they receive from their interaction with spouses, neighbors, and

extended families, which they report as mostly positive. The mothers in the current study demonstrated an ability to balance the demands of their multiple roles. In performing these roles, they derived two satisfactions: fulfillment of these multiple roles (providing them with a sense of purpose) and a sense of their abilities (physical and emotional capabilities), which contributed to feelings of competence.

Competence in turn is a predictor of self-esteem.

Affleck et al., (1989) found that mothers with high self-esteem were more self-sufficient and thus more satisfied with the support available. These concepts of self-esteem, self-sufficiency, and support are multidirectional in nature and all these influence and strengthen each other. Or, it might be that mothers who are satisfied with their social supports feel more confident and demonstrate positive self-perception, and therefore are better able to express their needs, more effectively attracting support (Fondacaro & Moos, 1987). Whatever the case may be, the commonsense view is that an individual's self-perception influences social supports. This study demonstrates that social supports are influenced by the individual's self-perception, and in turn become a motivational factor for the acceptance of and continued commitment to caring for a child with a disability

Seybold et al. (1991) and Blankfeld & Holanan, (1999) findings indicate that the effective support had a positive influence on self-esteem. In a study by Chen and Tang (1997), Chinese mothers received tangible, emotional and informational support mainly from family members that influence positively on their feelings about themselves. The results here contrast with those of Cant (1992), who found that siblings, friends and neighbors tend to distance themselves from families with a

disabled child. Because they felt that whatever assistance they provided would never be reciprocated that obviously created less support that influenced negatively on self-esteem. In this study, families rely on extended family, which was a cultural norm, and a result of intermarriages that ensured reciprocity. In fact, the influences of social supports on these mothers' self-esteem were perceived to be positive.

None of the mothers questioned Allah for giving them a child with a disability. Only one father and a sibling raised this question, but then immediately rationalized it. However, there is a strong sense in all the mothers that they have been entrusted with a special responsibility. As one mother stated, "Allah only knows why He has given me this responsibility." And the idea that the "child is a test" links the caregiver's responsibility to a religious understanding. Along with a sense of responsibility, the respondents perceived themselves as good mothers who hold no blame for the disability. All these beliefs influenced their perception of their competence to continuously commit to the care of the child. As a result, the mothers in this study were content to accept the fate within four walls their cultural and religious context creates for them.

Culturally and religiously, motherhood for women in the current study was without doubt an achievement in which they accepted the child's disability and continuously committed to his or her care. Society assigns roles and responsibilities by maintaining a status quo (detailed in the section on social support below). However, the strong desire of the women in this study to become mothers may not exist in different classes and among women with a different level of education. In Pakistan, 70% of the population lives in a rural context and 15% of the population

are in the lower socioeconomic classes. To round out this picture, 2% of women remain unmarried or separated, and only .7% are divorced. Women have an average of 6.5 children, according to UNICEF and the Government of Pakistan (Adeel & Naqvi, 1997; PARD, 1994). For the majority of women, poverty, illiteracy, and powerful societal values present substantial constraints (Weiss, 1991).

From a broader perspective, the structure of the society and belief systems ensured that the mothers were fulfilling the most important responsibility of their role as mothers: childbearing and child rearing. Vock (1988) calls households an important biological and labor reproductive unit for the society. However, the same society and belief systems overlook women's situation by neglecting their needs. It is well documented in Pakistani literature that the majority of women are poor, sick, and far less well educated than men (Adeel & Naqvi, 1997; PARD, 1994; Tinker, 1998). Their basic needs, such as education and health, are seldom met.

Religious beliefs underpin the status of mothers in particular and women in general. Islamic ideology gives equal rights to women, and as for a mother, paradise lies under her feet, but these beliefs are not evident in practice; instead the women are exploited on a daily basis. The contradictions between religious and ethnoreligious traditions are explicit in this study detailing how women live and are treated in a society that should, in light of its religious tradition, emphasize human rights and female equality.

The following section presents the cultural realities domain and the five themes that were identified therein.

3. CULTURAL REALITIES DOMAIN

The cultural realities for the mothers in this study include the daily routines, behaviors, values, and social systems that they are part of, abide by, and maintain. These systems, on one hand, support the care behaviors by regulating the mothers' roles. On the other hand, these systems are designed to provide a purpose and a direction to life by providing women who exist within four walls with a connection to and appreciation of social supports. These two dynamics of Pakistani society serve to strengthen and reinforce women's acceptance of their situation and continued commitment to care, often despite poor health. The five themes within this domain that were found to contribute to women's acceptance and continuous commitment to care are: (1) caring, (2) daily routines, (3) health issues, (4) *pir/faqueer*, and (5) social support.

Theme I: Caring

Traustadottir (1991), in a qualitative study on caring for children with disabilities, describes three types of caring. *Caring for* refers to the work associated with providing care. *Caring about* refers to the love for and relationship with the child with disability. In the *extended caring role*, mothers extend their care beyond their own child to broader community of societal concerns. Pot, Deeg, and van Dyck (2000) define care as the daily aspects of physical care such as bathing or feeding a person. Emotional health is described as threatened by lack of sleep, exhaustion, and limited time for other members of the family (Hilbert, Walker, & Rinehart, 2000). In this study, care includes feelings of concern, responsibility, and commitment to care;

the daily requirements involved in attending to the needs of a child with a disability; and the emotional aspects of caring, such as a tender touch, supportive talk, empathy, and affection provided face-to-face. Furthermore, it includes concern about dependency issues and hope for normalcy through continued pursuit of a cure.

The responsibilities involved in caring for children with disabilities grow more strenuous over time as caregiver age advances and caregivers' own health is affected (Milliken, 2001; Stephen, Townseud, Martire, & Druley, 2001). Physically, mothers are exhausted by activities such as giving a "shower every day" to three grown-up children, dressing them, which requires constant firm direction, and trying to "do everything for these children." Another mother caring for her menstruating daughter reported that she "does so with more responsibility than I devote to myself." All mothers referred to the unremitting attention that is required because of their child's susceptibility to disease: "with a little carelessness, Kashi gets sick and is admitted to hospital." Many narratives illustrated the physical aspects of caring and the difficulties mothers face in raising special children. Despite the overwhelming nature of such care, these mothers took pride in caring for their children.

Caring for a disabled child is not only laborious, but needs lots of patience and vigilance (Carr & Fogarty, 1999). Emotionally, these mothers are in distress over issues of dependency and vulnerability. As one mother put it "I and my family are very concerned and wonder what will happen to this child." Many mothers were worried about their children's behaviors because they required vigilance that is emotionally stressful. Comments such as "One has to be attentive to him all the time

so that he does not go outside” and “He is incontinent, makes mischief, bothers us a lot, he has broken very expensive things” were typical.

In some cases the behaviors of children were unpredictable and in others there were disability-specific behaviors (Vitaliano, Russo, Young, Becker & Maiuro, 1991). For example, one mother described some behaviors of her child that are typical of autism, although this child had never been diagnosed as autistic. To receive a diagnosis would not change the reality of this child and his family, because the supportive services that often result from a diagnosis in the West are not available in Pakistan. This mother lives with an adult who rocks constantly and bangs his head day and night. Managing this behavior would be difficult for any individual, and is compounded by living in a small house with seventeen other people, including two other disabled siblings. A Bangladeshi study indicates that the strongest predictor of maternal stress is child behavior problems (Mobarak, Khan, Munir, Zaman, & McConachi, 2000). Chinese mothers are also concerned about their children’s behavior problems (Chen & Tang, 1997). The irony of the situation of these mothers is that they cannot get away from their children because of societal expectations: their roles as a mother and a caregiver require them to provide care. These mothers do not have a choice not to attend to their child’s behavior, because there are neither respite services available for them nor any services for the children.

Normal children learn on an everyday basis and become more and more independent over the years. As the child grows, the mothers’ physical and emotional involvement diminishes, although it does not disappear completely. But the mothers in this study stayed on their feet to provide physical care and overcame stress to

provide emotional care to their children year after year, yet they did not consider that care to be a burden. The belief that they have been given the ability to care for their child, that their child is a gift of Allah, and that they are being tested by Allah in terms of how well they embrace this challenge—all these beliefs insured that their experience of caregiving was not negative.

Furthermore, these women worked very hard to provide care to large families, with no automated devices or outside help and with diverse logistical problems regarding water supply and power shortages, in addition to their poor health. This work was laborious and never ending, with no time or opportunity to acquire education, awareness, or entertainment. The women in this study were not aware of the possibilities that life might have for them; they were so engrossed in their menial tasks that they did not even have time or energy to reflect on their life situation.

Unfortunately, studies tend to highlight the numerous negative aspects of caring for children with disabilities (Cant, 1992; Chen & Tang, 1997; Damrosch & Perry, 1989; Hadadian, 1994; Seybold et al., 1991; Shearn & Todd, 1997; Vitaliano et al., 1991). However, parents in this study considered raising their child with special needs to be privilege rather than a problem. They utilized their personal resources and social support systems and found the experience of raising the child to be empowering. This study found that the attitudes and coping mechanisms of parents were influenced by many factors, including religious beliefs, cultural realities, and intrapersonal strength, values, and perspectives. A study in Hong Kong that examined children with developmental disabilities reported similar findings. The

authors found that successful parenting of these special children is accomplished because of parents' personal resources, such as their acceptance of the disability, and the extent to which they engage in advocacy and empowerment activities. Second, family and marital relationships are important in developing positive coping behaviors toward disabled child. Finally, a positive attitude toward life and strong feelings of the personal rewards associated with parenting contribute to the coping behavior of parents (Li-Tsang et al., 2001). These conclusions are similar to those arrived at within these pages, perhaps not surprisingly, as both studies were conducted within Asian communities.

Theme 2: Daily Routine

The mothers' daily routines consisted mostly of the chores they performed at home in the process of managing their households and caring for members of their immediate and extended families. Women's roles emerge in the traditional family in complex ways – either by performing routine activities in the household or by taking on any extra activities that occupy the mother emotionally or physically (Hart, 1994). The traditional Muslim family structure is based on a deep divide between the roles and responsibilities of male and female (Abu-Lughod 1985; Haj, 1992; Hijab, 1998). Women are expected to maintain the household, bring up children, and cater to the needs of men. This is a common expectation in many regions and countries of the world, such as in Morocco (Hart, 1994; Mernissi, 1987), India (Lateef, 1998; Memon, 1981), the Arab world (Al-Krenawi & Graham, 1999; Ab-Lughod, 1985; Goodwin, 1994; Hijab, 1998; Kandiyoti, 1988) and African countries (Sticher & Parpart, 1988).

Although their lifestyles were fairly urbanized the families represented in the study maintained very strong links with rural communities; they were in the transient phase of urbanization. Except for one the women did not work outside the home, and were very involved with their household responsibilities and extended families. It is not possible to say, from this study's findings, whether similar women who had no children with disabilities would have been involved with their extended families to the same extent. However, it is evident that the sample needed the involvement as a resource and safety net. In much the same way, Western mothers who have children with disabilities increase their contacts with community in an effort to find resources for themselves and their children (Traustadottir, 1991). Western women tend to access formal support systems whereas Pakistani women must rely on informal supports.

Theme 3: Health

Another aspect of the cultural realities domain, which overlaps with daily routine and chores and directly affects mothers' continuous commitment to care, was the health problems experienced by these mothers. Nine of the eleven women mentioned their physical problems without any leading inquiry and gave in-depth descriptions of their overwhelming health problems. This phenomenon has been discussed in detail in the Pakistani literature (Adeel & Naqvi, 1997; PARD, 1994; Tinker, 1998). The Western literature contained no such phenomenon, for obvious reasons. However, women's health is a common issue in the literatures of developing countries, such as Arab countries (El-Saadawi, 1997), Africa (Stichter & Parpart, 1988), and the Indian subcontinent (Adeel & Naqvi, 1997; Basu, 1999; Lateef, 1998;

Memon, 1981; Mumtaz & Shaheed, 1987; Nagaich, 1997; PARD, 1994; UNICEF, 1992)

It is clear that cultural practices and social settings influence women's health. Their health is related to awareness of nutrition and hygiene, availability of food and water, and access to health facilities. In Pakistan, cultural practices and the social position of women directly influence their health negatively. Society positions men as the head of the family, and hence their needs are given priority. All resources are first provided to men and then trickle down to women, including food, health and education services, transportation facilities, and so forth. While neither Islam nor the government wants women's needs to go unmet (Constitution, online; Hashmi, 2000; Hussain, 2001; Jawad, 1998; Khan, 1999; Mernissi, 1991), in practice their needs are simply not considered as important. Culturally, mothers observe *pardah*, and societal expectations for them are to make sacrifices for their spouses and children. *Pardah* is a system that defines and allocates roles, in which each gender has well-defined characteristics, behaviors, and prestige in the society (Khan, 1999; Mernissi, 1991; Williams, 1999; Winkvist & Akhtar, 1997). *Pardah* sets the limits to a women's mobility outside her four walls (Khan, 1999; Mernissi, 1975; Tinker, 1998; Winkvist & Akhtar, 1997).

When I went to the house of one of the mothers for the second interview an extended family member informed me that she was out. Disappointed, I turned and took the stairs down. Halfway down, I met her son Taqi, who he informed me that his mother was coming behind. By the time I reached the end of the stairs, the mother had appeared in *pardah*. She informed me, "I went to the clinic to get his

medicine—while there I saw the doctor myself.” In this instance, the mother had used her disabled child as an excuse to visit the doctor to see to her own health needs. Winkvist and Akhtar (1997) reported similar behavior in accessing health facilities by women in Punjab and the NWFP. Furthermore, healthcare professionals “recognized this as a means for the mothers to get access to a doctor.” The article further reported, “childless women have less access because children cannot be used as ‘excuse’ and they [childless women] were perceived to be not worth spending resources on” (Winkvist & Akhtar, 1997, p. 1488).

Another aspect of health is the expectation of maternal sacrifice, which includes sacrificing their share of limited resources to others. The role of a mother and wife is characterized by deferral to others in all aspects of life. Given limited resources, mothers would rather spend their time, money, and energy on the family than on themselves. As well, there are other issues, such as the availability and cost of babysitting, lack of transportation and the fear of going out alone (Tinker, 1998; UNICEF, 1992), that keep women at home isolated from medical facilities.

The literature contains many studies that look at the well-being of caregivers, including studies on parental stress (Decker et al., 1989; Dyson & Fewell, 1986; Hadadian, 1994; Young & Kahana, 1995) and the higher risk of emotional difficulties (Harris & McHale, 1989), but the physical health of caregivers has not been considered. It must be recognized, however, that physical problems are more prevalent in the developing world than in the West. Another explanation for this lack in the literature could be that the concept of stress is unknown to these mothers; they are simply cognizant of feeling exhausted or fatigued. These mothers do not know

how to verbalize the phenomenon of stress, but are able to describe their health problems. Is there any link between stress and the mothers' health problems? Is stress manifested through ill health within the confines of the Pakistani culture? Answers to these questions await further investigation and research.

In the literature on caregiving burden, a mother's mental health has always been a variable. Wikler, Wasow, and Hatfield (1981), Fraley (1986), Olshansky (1962), and Damrosch and Perry (1989) used the term "chronic sorrow" (introduced by Olshansky) to describe the pervasive psychological reaction experienced by parents of mentally retarded children. Phillips (1991) described the symptoms of chronic sorrow as being sadness, grief, frustration, anger, guilt, denial, and depression. One would think general sorrow or chronic sorrow would be evident in the narratives of the mothers in this study, but this was not the case. The reason for the absence of chronic sorrow could be extended family support and very strong religious belief systems, which provide a powerful rationale for mothers' acceptance and commitment to carrying out their duties (Black, 1999; Meyer, Kassebaum & Lobao, 2000; Miner & McKnight, 1999; Schmuck, 2000; Treloar, 1999;). Al-Krenawi and Graham's (1999b) study in Arab Muslim societies, that religion promotes the mental health of Muslims in times of crisis and disease is consistent with the findings of the present study.

Theme 4: *Pir/ Faqeer*

Many of the narratives in Chapter 4 used the terms *pir* and *faqeer*, which require further explication. A *Pir*, also called a *faqeer*, is a person who is viewed as a faith or spiritual healer. *Faqeers/pirs* are found throughout the Indo-Pakistan

subcontinent (Kinzie et al., 1976; Miles, 1988; Pfliegerer, 1988; Winkvist, & Akhtar, 1997; Unisa et al., 1990). There may be some distinction between *pir* and *faqeer* that current literature does not define and the narratives of this study do not specify, and so this work uses the terms interchangeably, although *pir/faqeer* is always a male. According to Eliade (1987), *pirs* (saints) have a particularly close relationship with Allah; they are, “one whose special closeness to divinity mediate[s] between the ordinary faithful and an all powerful and distant deity” (cited in Al-Krenawi & Graham, 1996, p. 179). *Pir/faqeer* are believed to have special healing powers and access to cures for psychic and sociopsychic disturbances (Al-Krenawi & Graham, 1996). *Pirs* are experts in religious rituals and lead ceremonies at the shrines where they live. *Pirs* also live in local neighborhoods where *sawalis* visit them to get a *taveez* (amulet) and to meet other spiritual needs. They do not ask anything for their services. Graham and Al-Krenawi (1996) also noted that *dervish* (an Arabic word for *faqeer*) do not ask for remuneration for their services. A typical *faqeer* does not care about worldly possessions and self-image. When found in the neighborhoods, *faqeeers* are singing or calling for Allah’s blessings. *Faqeer* earn their living from the offerings of *sawalis*, who usually make offerings of food or money to them and ask them to pray, especially for a particular person.

There is a strong wish among caregivers that the person with disability should become productive or least not be an economic liability (Miles, 1988). *Sawalis* visit children who are perceived to be *faqeer*, because they are seen as an intermediary between Allah and the people. This concept of intermediary is widespread and is an accepted practice in Pakistan. An example from the narratives

explains this practice and belief system; “People come to him so he can pray for them.” A couple came to one of the children in this study who was perceived as a *faqeer* and asked him to pray to Allah to give them a son. “He prayed and his prayers were heard,” proudly stated the mother. When the prayer materializes, the *sawalis* make further offerings to the child, and the child gets defined as productive by the proud parents. Additionally, the child’s ability to be heard by Allah positions him as close to Allah. Becoming a *pir*, therefore, elevates the status of the child (Graham & Al-Krenawi, 1996).

Literature from the Indo-Pakistan subcontinent confirms these findings regarding *pir/faqeer* (Campion & Bhugra, 1998; Lamber, 1997; Miles, 1988; Sembhi & Dein, 1998; Unisa et al., 1990; Winkvist & Akhtar, 1997). There are some folk beliefs that are widely accepted by the general public. According to these beliefs, a person with disabilities is “lucky” or “holy,” has “second sight” or an “extra sense,” and their presence may give protection against the “Evil Eye” (Miles, 1988). Sometimes a disabled child is viewed as a special blessing, which enhances the mother’s ability to accept and continuously commit to the child’s care. As one mother said, “Our families believe he has good fortune.” Another mother was not concerned about her child and gave an example of others of her family members that had disabilities. She indicated that those individuals had grown up to become *faqees*. As she stated, “he will become a *faqeer*, there is nothing wrong about it.”

The role of a *faqeer* enjoys legitimacy in the public perception (Al-Krenawi & Graham, 1999b; Unisa, 1990; Winkvist & Akhtar, 1997). It originated from Sufism (Pfleiderer, 1988). There is a contradiction here in that despite the perception

that the family is “fortunate” and a special child is “lucky” or “holy,” it is clear that becoming a *faqeer* is a way of coping with an unfortunate situation. Most parents would prefer having a child that could be educated to become a doctor or an engineer. As one mother stated, “I would like to see him like my other sons who are normal.” Despite being a legitimate and respected profession, it is not by choice that one’s child becomes *faqeer*; this is a profession that is considered only when the child is not capable of pursuing other careers. Therefore, people with disabilities who become *faqeer* or *pir* provide a way for their mothers to cope with the disability, for this theme overlaps with and reinforces the theme of *gift of Allah* and the concept of *ihsan*.

Why would mothers want their child with disability to be a *faqeer*? Many studies in the literature (Milliken, 2001; Stephens et al., 2001) report parental concerns over dependency issues. Many mothers and their families were constantly worried about the future of the child in the absence of rehabilitation programs or other services. Their child’s becoming a *faqeer* gives mothers some guarantee that the child will not only be able to earn an income but also be cared for by *sawalis*. This guarantee takes their mind off their biggest anxiety about their child’s future: when they will not be there to care for the child. The *faqeer* is a legitimate public figure that is seen as helpful to the public, and this shifts responsibility from a personal to a collective realm. In addition, the latent function of this shift is to give mothers a guarantee of a secure future for their child with a disability in the absence of formal programs and policies.

Theme 5: Social Support System

The final theme in the cultural realities domain refers to the emphasis on social supports in Pakistani society. The families in this sample are considered fairly urbanized because they are all first-generation urban dwellers who continue to have deep roots in and strong social ties with their villages. When they visit villages they are segregated according to gender and adhere to village values. Segregation based on gender is a norm illustrated by the narratives of the family members. All of daily life is governed by the separation of activities that results from the sexual division of labor (Haj, 1992; Kandiyoti, 1988).

In Islamabad, these families' social world is very fluid, and relatively informal and flexible, where everyone understands and adapts to the urban environment. Fathers of these children with disabilities are often employed in government services and work from 9 a.m. to 3 p. m. six days a week. To sustain urban economic systems, social rules are developed to maintain the functional stability of the domestic system. This setup is created to ensure that women stay at home and dedicate their lives to catering to their families, and by doing so keep their locus—home—an appealing, nurturing, and safe haven for all members of the family.

An extended family pattern was evident in this study. The family unit of these families is defined to include all members of a family who trace their blood lines to a single ancestor, thus forming a large human unit anthropologically known as a lineage or clan. In the villages, extended families live in a large compound that houses them adjacent to each other; they cooperate in their quest for survival. These

units are self-contained and self-sufficient, as indicated by the narratives. Most of the families in this sample are those who migrated to cities during the massive urbanization trend in Pakistan; however, they continue to have strong ties to their clan back in the villages. This link remains strong while the older generation is alive and begins fade after they die.

The relationship with extended family takes shape in three ways in this sample. The first is when three generations comprise a household including a married couple, their children, and their parents in different combinations, such as in Huma's, Fatima's, and Aysha's households. The second involves sharing one's accommodations with siblings or living jointly (sharing quarters) with related family, another common practice, as exemplified by the households of Anila, Aysha, Fatima, Mona, and Shabana. Finally, there were families who shared their accommodation with a younger generation (nieces and nephews, etc.) in order to provide them access to opportunities. Islamabad is a capital and a growing city that offers opportunities in education, health, and work as compared to rural areas. These family members would come to town seeking access to education or jobs. Such is the case in the households of Anila, Huma, Kausar, Mona, Tuba, and Zula, who customarily offered support to siblings, nephews, and nieces who were seeking education or jobs in Islamabad.

These families live in small housing units in typically overcrowded households (see Table 4.1). Weiss, in a study on the walled city of Lahore, makes the interesting point that "overcrowded living conditions become a form of social control in themselves" (1991, p. 259). Sharing one's household with extended family

members in small house enforces conformity to societal values for these mothers and their families.

As mentioned earlier, social support systems maintain a status quo with implications for acceptance of disability and continuous commitment to care, but that provides very limited opportunities to women. Any structure or system has two functions, manifest and latent. Social support is manifested in many ways, such as financial and emotional to the mothers of children with disabilities. One of the latent functions of a social support system is to regulate roles, responsibilities, and the interaction of its members. The structure also reinforces and maintains the values and beliefs within the system (Kuhn, 1962; Nilsson, 1991). Social values are the most powerful constraint on women (Weiss, 1991). Social support for the mothers in the current study both provides them with encouragement and motivation and ensures that these mothers fulfill their role and responsibilities. In other words, the mothers' beliefs both console them and further isolate them.

Poverty and illiteracy serve as constraints on women, and societal values are instrumental in hampering children from receiving an education, and hence relieving poverty. Education is key to an individual's social and personal development and therefore an essential element in the development of nations. It is well known that educational level is negatively correlated with women's fertility and the subsequent development of disabilities, and a positively correlated with nutrition, health, and therefore with the reduction of disabilities (Tinker, 1997; Weiss, 1999, 1991). Regarding education, one mother stated, "in our area educating women was not considered good. Education to women was not important although we used to have a

school close to our house, but our elder did not send me there.” This woman is referring to a common phenomenon in her culture: despite easy access to a school, a female child is not sent to receive an education. Lack of formal education does not mean that learning does not take place; in fact other female role models at home facilitate the learning of female children.

Pakistani society places women within four walls in order to fulfill the needs of family members, and in turn women receive social approval and status (Haj, 1992; Kandiyoti, 1988). Motherhood is appreciated by this society and is necessary for women’s own survival. Evident from the themes is that social support includes the approval mothers receive from their spouses, neighbors, and extended families. As a result, the theme of social support overlaps with the theme of motherhood, as social approval of their caring behaviors helped the mothers to carry out their continuous commitment to care.

The mothers of this study and their children did not always enjoy the support of others. One mother mentioned that the relationship with her husband was not very supportive. Extended family meant additional work and would sometimes visit when the woman was tired and did not want them. Adults were sometimes helpful but other times compared the disabled child to their own normal children, making insensitive observations, such as “at his age children are already doing this and that, and your child is not doing anything.” Another mother was very emotional in describing people’s treatment toward her child when he went out: “If you see my heart, slice it open and see it is all wounded. Even when someone points to my child—that seizes me inside.” Their social supports were not always helpful and

supportive, and at times brought more pain than comfort and more distress than tranquility. This mixed experience is a common feature of such social support relationships.

Social support is usually divided into formal and informal aspects. Formal support is almost non-existent in Pakistan; however, informal support was evident and plentiful. According to Gallagher et al. (1983), the main source of support for the families and mothers of disabled children in the United States is the mother's own mother, although the father's parents also contributed. In this sample, the parents of both parents were very involved as well as maternal and paternal uncles, aunts, and their children. One reason for this involvement is that the majority of couples are related to each other, and in fact are often first cousins to each other. In a society where there is no formal support system, these women learn that relationships are extremely important for women. Therefore, supporting the family as a cultural norm.

Intermarriage is a strong feature of effective social support. Arranged marriages are often to individuals within the external family, which is the case in this sample. As one father of a fifteen-year-old stated, "I gave my daughter in the family when she was grown up—I picked a boy and engaged them." This narrative shows that women (in fact, a child) did not have any influence over matters as personal as choice of a spouse. Weiss (1991), in her study on working women in Lahore, found that the fact of going out to work did not give a women any say about who she could marry. Kurian (1997) indicates that handicaps in a family disrupt marriage in Arab society, because of the fear that the disability is hereditary, causing the child's siblings difficulty in finding a suitor. Conversely, most of the siblings in this study

were already engaged at a very young age, within the family. One father explained that one benefit of intermarriage is that both families are aware of the characteristics of the children to be married together, their values and beliefs systems, and the financial worth of the respective families (and so the expectation for dowry is more realistic). However, the practice of intermarriages impedes the development of new values, ideas, and practices. It restricts the flow of new ideas into the family and hence old ways of life prevail.

The next chapter will present a discussion of this research study, offering conclusions, strengths and limitations, and implications for research, education, and the practice of social work.

Chapter 6

CONCLUSION

Caring is a universal experience that is mostly performed by women in all parts of the world. The aim of this study is to learn about the experiences of eleven mothers who provide care to children with disabilities who lived in Islamabad, Pakistan, by looking for interrelationships and patterns of care in this particular context. Three domains emerge from the narratives of the mothers: religious beliefs, intrapersonal issues, and cultural realities. The first domain had one major theme, *gift of Allah*. The second domain had two themes, *hope of cure* and *motherhood*. Finally, the third domain had five themes, *caring*, *daily routine*, *health*, *pir/faqeer*, and *social support*. From these domains surfaced many insights about the daily life experiences of the mothers in this study.

This chapter is organized in three sections: (1) discussion, (2) strengths and limitations, and (3) and implications. The Implications section has three parts dealing with research, education, and the practice of social work.

Discussion

The major finding of this research is that: Caring merges with rewards because of the strong religious underpinnings and cultural realities that influence the motherhood role and offer strength in accepting a child's disability and committing to the child's continuous care.

Caregiver burden has been defined with two components, objective and subjective. Here the focus will be on the concept of objective burden as discussed in

the literature. Walker et al. (1992, 5131) have synthesized the literature on burden and described it as “anxiety, tension, a feeling of being overwhelmed (Robinson, 1983), resentment (Archbold, 1983), emotional exhaustion, impatience, helplessness (Cicirelli, 1982), frustration, guilt, and irritation (Archbold, 1983)”. Furthermore, negative feeling toward the care receiver (Novak & Guest, 1989) “place caring in the context of relationships in which the norms of obligations and feelings of affection and resentment intertwine” (Baines et al., 1998, p. 5). Other descriptions include feelings of embarrassment, overload, being trapped, and resentment and exclusion (Vitaliano et al., 1991). The research on caregiving burden (Baines et al., 1997; George & Gwther, 1986; Grad & Sainsbury, 1968; Ilango & Niraala, 1992; Jones & Jones, 1994; Parks & Pilisuk 1991; Vijayalakshmi & Ramana, 1992; Zarit et al., 1980) has only looked into the negative aspects of caring, and, therefore only encompasses emotional stress. Caregiver burden appears in diverse definitions with multiple burden scales; however, these are primarily focused on negative outcomes.

Caring, in this study, has brought both tangible and intangible rewards despite hardships and sacrifices on the part of mothers. The mothers met the physical and emotional needs their children yet did not perceive them as a burden. This is because, first, there was no resentment of their responsibilities for care, and second, there was no sense of guilt for bearing a child with a disability nor was there blame by others. Furthermore, these women believed that Allah had given them the capability to strive harder for both tangible and intangible rewards, and for that they accepted the child’s disability and continuously committed to their care. This occurs

in a context with very little available in support services. Therefore, caregiver burden does not materialize in the presence of a powerful belief, in a child as a gift of Allah.

In Western literature, few studies utilize an interpretative paradigm to conduct research and present positive aspects of caring. Some research makes inquiries into the benefits and costs to mother and daughter dyads of caregiving and care receiving (Allen & Walker, 1992; Walker & Allen, 1991; Walker et al., 1992). Also considered were mothers who extended their role of caring to broader societal concerns (Traustadottir, 1991), the positive attitudes, beliefs, and coping mechanisms of parents (Li-Tsang et al., 2001), enhancement of personal resources and marital relationship (Yau & Li-Tsang, 1999), and empowering families of children with disabilities (McCallion & Toseland, 1993). The current study is the first research that examines the caregivers of children with disabilities from a holistic perspective in the light of religious beliefs, cultural practices, and societal values.

The difference between the term “caring” used in this study and “caregiver burden” as used in the literature (Baines et al., 1997; George & Gwther, 1986; Grad & Sainsbury, 1968; Jones & Jones, 1994; Park & Pilisuk 1991; Zarit et al., 1980) is that “caring” does not have the negative connotations that “burden” has. Taking care of one’s own children was perceived both as a mother’s right and an obligation for those mothers who were interviewed. A mother gains her social identity by performing her role to the best of her ability. As well, the difference between “caring” and “burden” was related to the strong religious underpinnings of motherhood in Pakistani culture (mentioned earlier). The concept of caring offers some tangible and intangible rewards compared to that of burden, which only

encompasses physical, financial, and emotional stress (Baines et al., 1997; Jones & Jones, 1994). Caring has been referred to in the literature as a “labor of love” (Finch & Groves, 1983), but this phrase still carries a negative connotation because of the use of the term “labor,” or hardship.

The concept of caregiver burden emerged around the second wave of feminism. Women in lower socioeconomic classes and rural women have always tended to work both in and outside the home while also caring for others in their household and presumably always experienced caregiver burden. But then many middle-class women started to work outside the home, as a result of a shift in societal values associated with the second wave of feminism (Harlan 1998). The concept of burden first appeared in the literature in the 1950s (Claussen & Yarrow, 1955) and the 1960s (Grad & Sainsbury, 1968). As middle-class women started working outside the home, caring began to be conceptualized as a burden, although not for women who lived in rural areas or lower class working women. There is not a single study on caregiver burden that has focused on rural populations who provide care to the aged, ill, or disabled. Rather, existing studies on caregiver burden are conducted in urbanized societies, primarily with Caucasian women, using samples that have diverse groups of caregivers, such as daughters, mothers, and paid and unpaid aides.

In the West, those mothers who care for children with disabilities and who can afford to provide care at home mostly choose to stay home (Traustadottir, 1991). This is true even of mothers who are educated and who had been working prior to the birth of the child. This suggests that in a society where the majority of women

have managed to enter the public arena of paid work, there remains a tremendous amount of pressure to provide care. The boundaries on women's roles have extended beyond the household in the West, but those boundaries are still very rigid with respect to caregiving and household responsibilities. Are these findings due to societal values or women's own choice? I think it is a combination, as no individual makes decisions in a vacuum, without being influenced by the social context.

A holistic perspective is required, as caring emerges from many layers of cultural practices, religious beliefs, and societal expectations and approval. The women in this study experienced hardship, both physical and emotional, in providing care. To provide care was to fulfill the societal expectation of motherhood, for which they received recognition, approval, and rewards. The caregiver burden literature, however, does not view this concept from a holistic perspective, but instead describes care as a linear relationship between the experiences of hardship and the ill effects of caregiver burden as a result of those experiences.

The Indo-Pakistani literature gives very little attention to the concept of caring. Pakistani studies (Badr-e-Maram & Edwin, 1982; El-Jalani, 1978; Miles, 1991; Miles, 1989, 1990, 1995) mostly focus on development issues regarding special education and cross-cultural and historical perspectives of disabilities. The few Indian studies (Bhat & Gauba, 1978; Ilango & Nirmala 1992; Pai & Kapoor, 1981; Singhi et al., 1990; Verma, 1978) that exist have tended to utilize a Western conceptualization framework and burden scales, which had to be translated into local languages. These studies found that burden of care or family burden was associated with chronic mental illness, but has limited relevance due to their emphasis on

empiricism and positivism and to the experimental and quasi-experimental research designs that were used.

The Western ideas of women's liberation and equality are also advocated by international agencies in developing countries, despite the fact that inequalities persist in all areas. Gender equality that would enhance women's status and increase production and commerce is the goal of this discourse. But Western women's struggle to achieve gender equality has not come without a cost: women who work outside the home must place limits on their traditional role as they step into a very competitive outside world and add to their responsibilities of household, children, and families. Instead of learning from the experience in the West, where political and financial equality between the genders has yet to materialize, international agencies take the same pathways in developing countries such as Pakistan.

This, of course, does not imply that when women stay home, problems cease. The essence of feminism lies in a woman's empowerment regardless of her decision to work in or out of the home. Every member of society, regardless of sex, skin color, or religion, should be given multiple opportunities for development. Society has to make provisions for all its members for work, education, health, and entertainment. Society must support and encourage the process of self-actualization in all women through nonjudgmental values and practices.

A feminist analysis argues that women are victimized in their role as caregivers, whether they are paid or volunteers. Feminists have perceived caregivers as victims because the role has been associated largely with the negative outcome of caregiver burden. This is a misrepresentation of the role as experienced by the

women in this study. Feminism is an epistemology that is “an attitude, a frame of mind that highlights the role of gender in understanding the organization of society” (Cooke, 1999, p. ix). This study instead takes a broader, holistic perspective that found the caregiver role to be very rich and dynamic, albeit involving hardships and sacrifices in daily life. It is a role that brings recognition, social approval and perceived rewards in eternal life. In this context, mothers found the strength to cope with their children’s disabilities. These mothers were mostly uninformed, unhealthy, and poor in comparison to their Western counterparts. However, they did not appear to be powerless or helpless; rather they were active, involved, and resilient. They were impressive in their acceptance and continuous commitment on many levels. In return, they gained relative power and bargained for higher status in their dual roles as mother and caregiver, even in light of their limited personal resources and subordinate position within a patriarchal society. The outcome of this study demonstrates how these mothers gained the strength for coping and were empowered to carry on with their remarkable job of caring for their children with disabilities.

From a feminist perspective of caring, I will argue that caring is an empowering experience for the mothers in this study. These mothers saw themselves as having a “natural” obligation to fulfill the responsibilities of caring for their children with disabilities. Caring is a source of satisfaction, social approval, and pride for women in a society where they have few meaningful roles, particularly lower class women. Most of these women did not work outside the home because of issues of *izat* (honor)—their employment would reflect badly on their husbands—and when women did go out to work, they worked in factories for low wages or in

the informal sector (in private homes, cleaning and washing clothes or working from their own home as an embroidery worker, or tailor). In the sample for this study, the only mother who worked outside the home worked as an *ayia* (cleaning lady) in a hospital on a rotating shift. The cultural reality of these women is that they do not have the education and skills to find better paying jobs. The question then arises, are these real choices for these women, to work within four walls providing care to their own families, or to work outside in the market economy? Perhaps these women could be empowered to make choices for themselves. For that, there must be a change in societal values in support of education and skill development for women.

The literature worldwide indicates that mothers are primarily assigned the task of childcare, and the findings of this study are consistent with this. In the West, despite a much greater emphasis on women's equality as compared to Pakistani society, societal values and expectations also regulate the role of motherhood. Therefore, the majority of Western women are involved in a mother/caregiver role even though they are financially and physically independent, have multiple opportunities, and most likely are free to make choices.

Feminism seeks justice particularly, but not necessarily only, for women. Feminism is a collection of philosophies, among which Islamic feminism is one whose worldview is driven by the Islamic ideology. According to Cooke, Islamic epistemology refers to "the expansion of their faith and not a rejection of it" (1999, p. 61). In a similar way, this study contributes to the expansion of boundaries of faith; however, the intent is not in any way to limit or reject the faith, but to extend understanding from the religious perspective.

The women in this study exercised very limited choices in matters regarding their own personal lives. This is not limited to the women of the current study but women in general as evident in Pakistani literature in Chapter 2. The social structure of the society is patriarchal, and women are expected to be submissive, passive, domestic, gentle, and sacrificing (Farhat, 1999). These women's lives are governed by values and practices that have been well established for some time. They are not encouraged to avail themselves of education, a practice that effectively holds them back in all walks of life. The women in this study were married, without their consent, to members of their extended family, by their parents and bore many children in the hope of having many sons. This study also provides a window to a bigger picture of women in general. Women are passive doers who fulfill every command, no matter how detrimental to their own life. They serve others before they meet their own needs. The majority of Pakistani women are brought up in seclusion, and unexposed to alternative ways, and therefore never learn to take the risks involved in decision-making. These women seem to lack competence about having a say in any matter because they are illiterate, unaware and uneducated, (as Pakistani literature points out) not because of their own incapacity to learn, experience, or explore the world, but because they are given no opportunity to do so. Even those who have the opportunity are constantly reminded, through social mores and beliefs that their place is within four walls, raising children.

Conformity to cultural norms takes place early in a child's development. Individuals learn, from an early age, to conform and are discouraged from questioning norms. They grow up not considering or knowing of alternative ways,

and their choices remain limited. Society imposes, implements, and justifies beliefs that then become the way of life. Young men and women adhere to the same gender practices as their parents, and then teach these practices to their children. All these cultural mores and societal norms offer women minimal personal growth opportunities and services, which can facilitate personal decision-making. In general, Pakistani women have limited control over themselves within their four walls.

Nevertheless, these women should not be perceived as powerless, as they have some control over their context and relationships. Furthermore, religion in theory safeguards their rights and provides them with equal rights in matters of daily living such as education, food, choice of partners, divorce and access to the outside world (Ahmed, 1992; Hashmi, 2000; Mernissi, 1991). Culturally, they have excellent support networks among female neighbors and extended family that offer them emotional and social strength (Shaheed, 1995). These women negotiate their social position through their dedication and devotion to motherhood and caregiver roles. As well, their child with a disability gives them power in their relationship with their spouses, and their responsibilities to extended family members influence their relationships with other extended family members. In this closed and secluded context, women form strong networks that are utilized in the dissemination of information. Such networks could also be used to raise awareness. The presence of just one educated woman could serve as a role model and raise the awareness of other women about their choices and open up additional life possibilities. Education does not necessarily equate to awareness. Some forms of education actually restrict

awareness by insisting on a narrow and rigid perspective of worldviews. However other forms of education succeed in fostering a broader perspective.

Cultural practices affect the perspectives of society members on many different levels. For example, the cultural practice of mothers eating only after serving food to all other members of the family physically courts malnutrition and symbolically promotes the subjugation of one gender. When a woman's basic needs (such as food, education, and health) go unmet she learns not to expect her needs to be met, makes no demands, and stays compliant from childhood. These mothers grow up understanding from their own experiences, role models, and societal values, that they have minimal status, and consequently they behave in a docile and subservient manner. As well, in an environment with such a powerful communal ethos, individuals become enmeshed and lose elements of their individuality. Pakistani society gives very limited choices, voice, and decision-making powers to women, a position that is justified by the generational mores and beliefs that perpetuate this social injustice. The mothers' narratives clearly reflect their obsession with living up to the social image of themselves as thoughtful wives, devoted caregivers, and selfless mothers which precludes any opportunity for self-realization or self-fulfillment. Perhaps it is up to those with awareness and understanding of these issues to challenge these societal values, practices, and behaviors. By virtue of being educated and aware, these individuals become responsible for raising the consciousness of Pakistani society by suggesting ways and means to eradicate practices that disadvantage women.

The Constitution of Pakistan gives equal fundamental rights to both genders.

It provides for full participation of women in all spheres of national life (Constitution, online). However, the nation pays an economic cost for the cultural norm that keeps women confined within four walls and estranged from social development, since they do not contribute to industrial development and commercial production. It may be that the mothers in this study are aware of neither alternative ways of being nor their own potential as individuals. With no education or awareness, no services or resources, and no personal development opportunities, household labor is their only work and raising their children their only means of exerting control (Haj, 1992; Kandiyoti, 1988). The societal pressure on women hinders their ability to contribute to social growth and obstructs the road to social development in Pakistan. If women were offered better opportunities in their communities, perhaps a greater national vision for equality, prosperity, and social development could be realized.

Additionally, globalization is the new world order that requires and promotes social development. Social development reflects “a process of planned social change designed to promote the well being of the population as a whole, in conjunction with a process of economic development” (Midgley, 1995, p. 25). Globalization encourages competition among nations for the resources of the world (Wilson & Whitmore, 2000). To compete in this new world order, every member of the society needs to be well equipped through education, skills and decision-making power. No social order can afford half its population to be unable to contribute to its economic development. Pakistan must meet the needs of women and increase their partnership

in economic arenas to enhance the process of social development. Otherwise, this nation will lag behind in the new order, as it does not have any other natural resources to fall back on.

Strengths and Limitations

Ethnography is expected to create new concepts using anthropological traditions (Agar, 1996). Strengths were found in the conceptual and methodical framework of this study, while limitations arose from the mode of sampling and the issues of transferability that are inherent in qualitative research.

Strengths: Although the social and cultural realities of the West are entirely different from those of Pakistan, this study adds to the general body of knowledge in three ways: (1) a new dimension is added to caring that expands the conceptual framework; (2) this ethnographic study explores a particular social issue and advocates for change; and (3) this study raises a question regarding the issue of translation.

The caregiver burden literature has always associated caring with negative phenomena (physical/objective) and symptoms (emotional/subjective). This study adds positive aspects to the concept of caring and shows balance in the life of caregivers from their own perspective. The informants of this study perceived caring as having some tangible and intangible rewards. The tangible rewards included their status within their roles, social support, and social approval they derived from looking after a child with a disability. In addition, they believed in intangible rewards that will follow in this life and the afterlife. These intangible rewards gave mothers

the strength to cope, a notion that is a major theoretical gain to the literature on burden.

Conceptually, burden has been expanded beyond the Western understanding. Cross-cultural literature is breaking new ground because of migration trends in North America. People from the Indo-Pakistan subcontinent and other developing nations comprise the bulk of immigrants. The assimilation of new immigrants within a culture takes place gradually. In the meantime, Western professionals who deal with immigrant caregivers providing care to disabled and aging populations can better understand the religious and cultural aspects that govern caring behaviors.

Another population that will benefit from this study is students from the developing world. With high trends in migration, more and more ethnic groups are enrolling in higher education. Those immigrant students who pursue cultural studies will be tapping into various ethnic populations to understand caring from many different perspectives as they conduct research into the beliefs and practices of their country of origin. The expansion of the concept that took place through the inclusion of the religious and cultural context in the present study is advantageous in understanding different worldviews among ethnic populations. This research study was a small but essential step in expanding the conceptual framework of caregiver burden by introducing themes such as *gift of Allah*, informal social support, and faith healing notions that reach beyond the typical concept of caregiving burden in Western research.

Two new concepts for the Pakistani literature emerge: caregiver burden and caring with strong religious underpinnings. This research will help to guide future research in Pakistan, conceptually and methodologically. The concept of burden associated with caring will contribute to Pakistani literature. It is hoped that it will significantly contribute to the general awareness of some of the social issues in Pakistan in regard to disabilities and caregivers in particular. The religious underpinnings associated with caring will explicate the coping mechanism of caring in the presence of burden.

Methodologically, this research fills a gap in two areas, method and sample. Ethnography deals with cultures, language, and behavior patterns; however, this method is very seldom utilized by social workers in examining social issues of different cultures and in recommending services. This study contributes to the ethnographic literature by exploring social issues such as caring that are implicit to different cultures, and offers a contextual understanding by virtue of the method. Furthermore, this approach informs about opportunities for social change and recommends services for the population studied.

The informants in this study spoke Urdu. The transcripts were translated to English, using a very basic method of translation devised for this study. In going through the exercise of translation, I raised some questions that were important for the integrity of data. Raising the issue of translation invites multilingual researchers to explore this methodological issue, which is important in cross-cultural research.

Limitations: This study is limited by its research sample, which is a convenience sample and reflects a specific time in the life of the informants, and therefore cannot be generalized: “One cannot replicate an ethnography, since there is no way to capture time” (Germain, 1996, p. 159). This is especially true in a changing societal context where Pakistani women find themselves caught in a dilemma between home and workforce and, moreover, where the prevalence of disabilities is very high. However, there are many countries in the developing world that have conditions similar to Pakistan, and this study contributes to an understanding of mothers who care for children with disabilities in these contexts. Although qualitative research does not make claims to applicability and transferability, if one is careful to consider similarities in behavior patterns, religious beliefs, cultural norms, and social systems, some themes may be comparable in cross-cultural research.

Another limitation of this study is the over-representation of boys, a fact that has some implications in a Pakistani society (discussed in the Implications for further research section below). The sample ratio of boys to girls does not reflect national ratios. The ratio of boys to girls was two to one (see Table 3.1), a number that conflicts with the national census of disabilities, in which girls slightly outnumbered boys. One reason for this could be that this was a convenience sample, and more parents of boys opted to come forward for this research project. Culturally, male children are often considered better than female children; perhaps these parents did not hesitate to bring their sons forward, even if they were disabled. Furthermore, males, in Pakistani society by definition, take control of the outside world (Farhat,

1999). As such, they are expected to be familiar with the outside world, and this research provided them with an opportunity to be introduced beyond their schools and neighborhoods. Girls, on the other hand, are expected to remain within four walls performing the roles of daughter, wife, and mother. They are expected to stay in seclusion, protected and away from the eyes of the world—whether or not they have a disability.

Another important limitation to consider arises from convenience sampling. If the sample had included mothers of different classes, religious beliefs, financial statuses and societal values, the findings might have been very different. These findings represent the realities of mothers with low socioeconomic status and limited personal resources who maintain strong rural connections with extended family.

Finally, there is a conceptual issue arising from the use of language and the conceptualization of status. Translation is pivotal to developing the conceptual framework, and therefore to the reliability of the findings. During this research it became evident that the women in this study do not understand status in the same way, as do those in the West. In Urdu the word for status is *rutba*, a word not commonly used; most Pakistanis have never heard this word. The most commonly encountered use of this word was in regard to saints or prophets, who are perceived to have higher *rutba* in the eyes of Allah than ordinary people. Some of the respondents of this study understood this word in this way and their remarks reflected their view of their status in the eyes of Allah. Most of the mothers did not understand this term to be referring to their social status in relation to other groups in

Pakistan. They responded to questions about status in a way that took a different focus from the one intended.

In addition, status is defined differently in the Pakistani context, and its definition also varies with the education and work status of a woman. For all the women in the sample, status was manifested by their roles in a society; mother, wife, and daughter/sister. These women performed different interpersonal roles within their four walls. Role identification gave them self-worth and connected them to resources (i.g., men). These mothers may be poor, sick, and uneducated, living in a small house and performing household chores all day, yet they perceive themselves to have high status within their roles of mother, wife, and caregiver. This illustrates the importance of perception and how language reflects the conceptual underpinnings of the people who were studied.

Implications

The aim of this research is to develop insight and understanding in order to advance knowledge and influence life in a positive way. It takes a long time for societal change to occur; however, ultimately research provides information that can promote change. Ethnography can inform opportunities to make social change (Agar, 1996). The aim of this study was also to make transparent the experience of mothers who care for children with disabilities, and to suggest changes.

Implications for Further Research: This study was conducted using eleven mothers who live in Islamabad, Pakistan, who are of low socioeconomic status with minimal education, except one woman who belongs to the middle class and another

woman who had a high school education. This study focused on mothers who cared for children with disabilities.

Future studies using an ethnographic method to explore caring responsibilities might include a more heterogeneous sample, such as women of different ethnic and/or age groups, education, and class, and children who have severe or mild mental retardation or who are physically handicapped, and, might focus on gender. Future studies in this area are worthwhile because the data would expand the themes and enable a fuller illumination of the role of caregiver. A substantive understanding about caregivers in a variety of cultures may then be developed.

In a cross-cultural study language confines concepts in the process of translation. For example, “extended family” refers to a singular unit in the English language; however, in reality these are many independent units. These units represent different ages, from grandparents to grandchildren; diverse financial status, from high to middle to low class; and various religious beliefs and values, from conservative to liberal and radical. With all this diversity, they are still grouped as one extended family. To the contrary, this sample treats extended family as different units of families and deals not with one extended family but diverse families. Yet translation, mandating the use of the phrase “extended family,” to indicate all the diverse families surrounding a single nuclear family imposes an understanding of that concept drawn from Western culture.

One concern in this study was the translation of transcripts into English. In the shrinking boundaries of the world, the process of inquiry is expanding to

consider different areas, people, and languages of the world. Both inquirers and informants can be found in a variety of contexts and cultures with diverse languages, making translation skills an essential tool that adds to the reliability and validity of the data. The processes involved in translation needs attention in the literature and emphasis in research design. This study raises questions regarding translation and invites cross-cultural researchers who make use of translation as a tool to present their stories.

Another issue was the conceptual framework. The concept of caregiver burden is presented in a linear way; it has been conceptualized with social, emotional, and financial dimensions that point toward negative outcomes. Caregiver burden when caring for a child with a disability has never been connected to the role of motherhood or presented in the context of religious beliefs. These were two of the new findings of this research. The conceptual difference between burden and caring was discussed above. In this study, the term “caring” rather than “burden” was used to illustrate a more holistic and balanced perspective on caring. Caring had some of the characteristics noted in caregiver burden; however, feelings of resentment and guilt were not attached to the caregiving role. In the context of these mothers, the absence of these characteristics is the result of strong religious underpinnings. These mothers believe that the child with a disability is a gift of Allah, a concept new to the literature. This study’s findings reflect some positive contextual meanings of the role of caregiver, and remind researchers of the importance of considering the context of the group under study.

More qualitative research needs to be undertaken to examine caregiving burden because this method is the most appropriate method of inquiry into cross-cultural burden research, due to the nature of its assumptions, such as multiple realities, inquirer-subject relationships, and nature-of-truth statements. Ethnography is the best way to understand the context of caregivers from non-Western cultures. The concept of multiple realities in which no one perspective may be considered more true than any other yields a better understanding of the phenomena of acceptance of a child's disability and continuous commitment to care in a cultural and religious context that offers very limited choices. It has provided mothers with coping strategies that are very different in nature from those in Western experience, and needs further exploring.

There is a dearth of research on the conceptualization and operationalization of women's status that considers all aspects of their role. The construct of status is comprised of both tangible and intangible aspects. Tangible aspects include money, education, health, mobility, and so forth, whereas intangible aspects include love, non-judgmental respect, support of extended family, spirituality, sense of self, interdependence and other such elements. Hence, both parts are representative of the whole construct of status, and any adequate understanding of this concept needs to encompass both essentials. When researchers ignore intangible aspects of the concept, this threatens the meaning and interpretation of this concept in any context.

Theory-building endeavors should encourage the development of impartial perspectives grounded in the context of the participants rather than perpetuating stereotypical themes. Theories should consider an efficacious perspective rather than

reinforcing a pathological perspective of a culture. An inquiry should focus on the lived realities of women in accordance with their roles in that culture. The Western concept of women working outside the home should not be the conceptual framework used for determining women's status in other cultures. Cultural and religious realities should take precedence in theories that represent Third World cross-cultural perspectives.

In addition, further research needs to be conducted in identifying issues related to stress. Researchers need to take culture into consideration in any exploration of how stress manifests in different context, such as Pakistan. Questions to consider could include how stress is manifested in women who deal with poor physical health, and how they cope with stress within the bounds of their culture.

Implications for social work Education: This study recommends broadening the scope of social work education in Pakistan. For this to be accomplished, undergraduate education needs to implement a generalist practice framework with one-third of the student's time spent in field or agencies with one-on-one contact with the client population. For graduate education, the recommendation is to take a broader direction in clinical, research, and policy arenas and for graduates to be able to serve communities on micro, mezzo, and macro levels.

Two areas that need special emphasis in Pakistani social work education are policy and research. In order for social workers to activate social change, advocacy is imperative. To successfully advocate for a process, social workers' representation in decision-making processes is key. Research is an essential tool to develop

understanding, draw conclusions, identify relevant social issues, and ultimately to bring about change. These recommended changes are important in establishing the field of social work as a recognized profession.

In the West, social work education benefits on many levels. The results of social work research provide a new understanding about Islam in a social work practice context, in an era of increased globalization through enhanced information systems, travel opportunities, and economic interdependence. The social work profession is gearing up to meet new global challenges because of the interdependence of national, continental, and cultural systems. This study provides students an opportunity to see the world from a systemic perspective, and will increase international awareness on different levels, such as those of religion, culture, economics, and politics.

Expanding international trade is a reality that affects national economies throughout the world. Few students are aware of the social and economic injustices that go on in support of economic development. As nations become ever more interdependent in this new world order, there is a greater need to be aware of structural poverty and injustice. Studies such as this offer exposure to religious beliefs, cultural values and societal practices that may hinder social development and therefore contribute to the continuation of structural poverty and injustice on the macro level.

Students in the clinical stream require an awareness of diverse cultural issues, and this study provides contextual information that may be of value. The understanding provided of Islamic beliefs, in an era of increased immigration trends,

yields a greater knowledge base and possibly resulting skills to deal with issues that arise in clinical settings.

Finally, this study provides a method of inquiry for non-Western cultures and raises issues regarding language, translation and the conceptual gap that exists between East and West. For the increased numbers, of immigrant students accessing higher education and deciding to complete research in their own cultural context, this study identifies important issues in relation to research design and literature.

Implications for Social Work Practice: A major implication for practice in Pakistan is that social workers need to take leadership roles in their communities to advocate for and provide services in areas such as mental health, disabilities, women's issues, health, and education. This study made clear the kind of services these mothers needed, although the participants were not aware that these services could exist. It is clear that in Pakistan, formal policies on disabilities and special education are rudimentary or lacking (Miles, 1989). There is a great need for outreach programs and advocacy. Trained social workers are required to provide service delivery, to meet advocacy needs, and to develop and implement policy and programs. Policy and program development models should focus on building upon the "natural helping structures" that are already in place. The following are some concrete recommendations for services in light of the local conditions.

The Pakistan government is unable to allocate enough money to the social problems arising from disabilities because they are confronted with problems of higher priority, such as health, education, and economic issues. In a situation like this, they can use existing infrastructures for the benefit of caregivers who provide

care to children with disabilities. Pakistan has built huge schools, many of which are not fully utilized and which could be used in providing services for caregivers. The government has developed transportation systems that could be used to transport caregivers. The delivery of services could be generated from the space, services, and staff already on hand in special education schools.

Many strong socioreligious structures exist in Pakistan that encourage acts of *sadqa* and *kharat* (charity) toward people in general as well as toward those with special needs (Al-Abdul Jabbar & Al-Issa, 2000). The *sadqa* can take many forms: time, space, money, looking after someone, or just being considerate. This religious practice could be utilized in motivating people to volunteer for special schools, establishing and raising funds to provide services for caregivers.

Recommendation of Services:

The following section outlines some of the services that the mothers mentioned in their interviews. The mothers of this study were not aware of any existing services; however, they did mention their concerns, which have been shaped into these recommendations.

Greater emphasis on training. Greater emphasis on training in assessment and diagnosis is required. There is a need for effective efforts to identify psychosocial instruments that assess the strengths and challenges of special education students. The established method of assessment is very basic, and insufficient to understand the needs of a child with a disability. This lack of skills in the evaluation and diagnosis of disabilities limits the ability of existing services to

meet the needs of students. The key is to accurately assess the needs of mothers and children so professionals can identify and deliver the required services.

Health professional schools (i.e., medical, social work, nursing) need to train health professionals specifically in the field of disabilities. In rural Pakistan, health agencies need to provide training to health workers and midwives, and to utilize existing rural health networks to provide education and awareness of services to rural populations.

Full Participation. Full participation, or mainstreaming, is an important aspect in the development of individuals and society as whole. Both individuals and society gain from a policy of inclusion. Inclusion refers to full participation of a disabled person in social, economic, and political settings. Inclusion enhances learning for both special needs and healthy children and adults in a society that is at an early stage of recognizing disabilities as well as the important role of caregivers as social issues.

A greater awareness of disabilities among the general public would increase the public sense of responsibility toward those with disabilities. This would provide the disabled with better integration and acceptance into society and allow mothers to take their children out of their homes into public places without anxiety, as well as decreasing the current uneasiness around people with disabilities. For this to occur, parental involvement must be encouraged in schools and other programs on individual and collective levels, and parents must be given an opportunity to voice their concerns.

Another important policy that would support mainstreaming is to give people with disabilities access to each and every amenity—buildings, parks, arenas, and the like. Discounts should be offered on public transportation, and to sports and cultural events and so forth. This would provide an initiative to parents to take their children to public areas, smoothing the process of inclusion and encouraging the full participation of children.

Information and referral. The Special Education Directorate needs to streamline admission procedures in the special education schools that children with disabilities attend. These procedures should be common knowledge to the general public in order to facilitate easy access to special resources. In addition, NGOs should be mandated by law to provide a certain number of services at no cost (such as diagnostic service, awareness, and advocacy) until the government can provide services to the larger population.

Information and referral services could be established at schools, mosques, hospitals and other locations that are accessible to the general public. Information on fee-for-service resources should be compiled and made available to the public. The media could be utilized to provide information on resources and to raise awareness about disabilities.

Another important cultural practice that is widespread is the lack of education and awareness regarding marriage practices. As we have seen, eight of the eleven couples in the sample had intermarried – the wives and husbands were cousins, and sometimes double cousins. These families were unaware that this practice presents increased risks to their offspring. These couples were adamant in favor of marrying

within their own families and intend to arrange their children's marriages in this way. Public education and awareness should target this issue nationally through mass media. More scientific information on the causes of disabilities needs to be provided to the public, perhaps through rural and urban educational systems.

Finally, information about maternal health should be provided to the public. Maternal health is directly affected by prenatal nutrition, the amount of physical work women do, the quality of prenatal care they receive for complications that may arise during pregnancy and childbirth, the number of children conceived, the interval between pregnancies, and whether or not they breastfeed or practice contraception. Other factors that influence maternal and children's health are whether or not a woman seeks antenatal care and whether she opts to deliver her child at home using a traditional birth attendant or at a hospital or clinic with a doctor in attendance. All these aspects are important for maternal health and require widespread educational efforts. Governments need to inform the public about the causes of high maternal mortality and place emphasis on policy making, planning, and developing and implementing projects that aim at improving maternal health and reducing morbidity and mortality.

In conclusion, Islam is the fastest growing religion in America (Encyclopedia Britannica, 1997), and within it Muslim women are gaining prominence (Twair, 2001). To immigrant Muslim women, faith is a guiding element in negotiating and coping with the drastic cultural differences between Eastern and Western cultures. Sheridan, Bullis, Adcock, Berlin, and Miller (1992) assert that Western social workers appear to have little training in religious issues (cited in Al-Krenawi &

Graham, 2000). As noted, caregivers are mostly women worldwide, and therefore Western Muslim women will not be exempted from the role of caregiver. This is the first study that focuses on the significance to social work practice of the role of caregivers from an Islamic perspective. The Muslim population is significantly underrepresented in literature on the family (Carolan et al., 2000). The themes that emerged in this study set the stage for social work practice with Western Muslim clients, which will inevitably encounter the centrality of Islam in daily life.

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APPENDIX A: CONSENT FORM

My name is Saira Zaidi, and I am a student of University of Calgary, Canada. I am here to conduct a research study. The purpose of the study is to better understand your role with the joys you derive from and the struggles you go through in providing the best care and nurturing to your children in this culture and socioeconomic setting.

I am requesting you to participate in this study. During the research I will interview you and spend time in the school with your child and the school staff. I will take pictures during this process. I will also visit you at home to observe the family dynamic and household setting.

For participation in this study you will not get any monetary compensation. There is no risk involved except that I require your time for interviews. You are free to participate and at any time during the study if you decide to drop out of this study for any reason, you may do so without any consequences. Your participation is voluntary and having your and your family picture taken is also voluntary. The only benefit you might get out of this study is supportive counseling and recommendations made to DSE that may or may not be implemented. However this study will provide me with an opportunity to learn and develop.

Your name or identity will not show on any paper. All your personal information and photos will be confidential and only access to me and only used for educational purposes.

My local contact phone no is 212606. You have any question or concern, you may contact my supervisor by email william@uclagary.ca or phone: (403) 220-8288.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation and agreed to participate as a subject. In no way does this waive your legal rights nor release Saira Zaidi or Uof C from their legal and professional responsibilities.

Participant Signature

Date

- A copy of this form has been given to you for your record and reference
- If you would like to have a copy of the findings of this research, please provide your address: _____

APPENDIX B: STORIES OF MOTHERS

Anila:

Anila is 32 years old. She has a primary education and is not employed outside of the home. In her sixteen years of marriage she has had four children, all boys, presently ranging from 5 to 14 years in age. Her child with a disability is Adnan who is 10. His disability was detected because he was delayed in talking as compared to other children in the family. She needs to supervise him very closely and does not let him go outside of the home to play in the neighborhood as he gets in trouble with other children. She has to assist him in his daily living activities, such as, bath, meals, dressing and so forth.

Anila shares her house with her sister's family. The sister and her family live in the downstairs portion of the house, Anila's family lives in the upstairs portion. Anila's husband has his own business of metal polishing, where the sister's husband works, also. The business is not providing well for these two families, which is why both are having financial hardships. Anila's husband also supports his own father who lives in a different town.

Aysha:

Aysha is 35 years old. She has completed the 10th grade and is not employed outside her home. She is attending a beautician's academy to become a beautician. In her 14 years of marriage she has had four children, all boys, of whom the first-born died at the age of six months. The remaining boys' ages range from 7 to 13. Her child with a disability is Arslan who is 12 and is enrolled in Ibna-I-Sana school. His disability was detected when he was three as he was still not talking and constantly banged his head against the wall. He needs close supervision and assistance with daily living activities.

Aysha's family shares a rented house with two of Aysha's brothers and their families and Aysha's mother. One brother has four children and the other has three children. Aysha's husband operates an elevator in a hospital and it is not a permanent job. Aysha and her family are largely dependent for financial and social support upon her brothers' families.

Fatima:

Fatima is the 52-year-old mother of ten children. She has primary education and is not employed outside of her home. She has been married for 38 years. Of her ten living children, three are disabled. They are Atif who is 28, Kaksha who is 24, and Fasal who is 18. All three children, Fatima and her family live in government housing on a very busy road. Fatima shares her house with seven grown up children of whom two have families. The oldest son has four children. Her second son has a

daughter. Her husband had retired from a government job. In all, there are seven children and ten adults who are housed in an apartment with four rooms and one bathroom.

Two of Fatima's normal children go to college and Fasal is enrolled in Fatima Jinnah School. I made four visits to their house. On my third visit, we had planned to visit a needy family in Shahpure village. We went together and took some supplies, clothing, and financial aid for the family, which had with three disabled children. On my other three visits I observed Fatima's strong commitment and purpose toward her children, both normal and disabled. She exudes a sense of family and an overwhelming sense of security in her role as a mother and a caregiver, while receiving little emotional support from her husband. All her three disabled children are very needy and need assistance with their daily living activities.

Huma:

Huma is the 42-year-old mother of seven living children. She has a primary education, and is not employed outside of her home. She has been married for 26 years and has had eleven children, of whom four have died. Her remaining children include two daughters and five sons, ranging in age from 6 to 25. The child with a disability is Haroon who is 10 years old. Three years ago, Huma detected Haroon's disability by comparing him to his younger brother. All this time he had been going to a regular school. Haroon needs supervision all the time, as he tends to wander out of his house. Huma provides all daily living activities for Haroon. Huma and her family share the house with her father-in-law. Huma has five sisters and one brother. They all live in the same neighborhood. Haroon is enrolled in Ibna-I-Sana School. Six of Huma's children are in educational institutions while the oldest is a mujahadeen

Kausar:

Kausar is a 37-year-old mother of five children. She is illiterate and employed in a government hospital as a nurses' aide. She is scheduled to work on different shifts every week. She has two daughters and three sons, ranging in age from 13-18 years. The disabled child is daughter Kiran, who is 13. The parents believe that she was exposed to a 'saya' (a mysterious evil shadow) while outside.

Kausar lives in Lal (Red) quarters, which are poorly maintained government housing and as the name suggests, are colored red. They are small and old; during rains, the roof leaks and the yard is waterlogged. They have extended families that constantly keep in touch, which becomes a problem at times for the family.

Kiran is enrolled in Ibna-I-Sana School. Kiran is a very sweet little girl who is capable of caring for her self and is quite independent. Kausar's husband works for the government as a driver. Both parents have stable jobs with benefits

Mona:

Mona is the 31-year-old mother of five daughters. She has a primary education and is not employed outside of her home. She has been married for 14 years. Her daughters' ages range from 1 to 12 years. Mamoonah, 11, is her second daughter and the child with a disability. Mona said they knew Mamoonah was slow to learn; however, they sent her to a regular school for three years. When she learned nothing, it indicated to them that there was a more serious problem.

Mona and her family live on the second floor of a government apartment complex. Her divorced sister and a brother also live in the apartment. Being the oldest, Mona has supported all of her siblings and is still supporting two of them. Mona's husband works for the postal service, and in the evenings, helps the homeopathic doctor who sits in the government clinic at the complex. Mona has been struggling with a chronic health issue for the past five years, but due to limited resources, lack of transportation, and babysitting issues, she cannot continue treatment for as long as she needs to. Treatment will be pursued when her health issues become acute.

Mamoonah is enrolled in Ibna-I-Saa School. She is very dependent on her mother, needs very close supervision and cannot perform daily living activities. Mona has to provide care to her as if she were a toddler.

Nadia:

Nadia is a 41-year-old mother of three children, all disabled. She has a college education and used to work for the Pakistan Energy Commission. She quit her job to care for her three disabled children. Naeem is her 14-year-old son, Bilal is her 12-year-old son, and Hina is her 6-year-old daughter. Nadia has been married for 16 years. She wants to have a normal child but the doctors have discouraged her and will give her no guarantees. She believes that a normal child would take over her burden and look after her disabled children when she dies. Having had no prior experience with disabilities, she detected her children's disabilities very late.

Nadia and her husband own the two-bedroom house they live in and the small plot of land it is built on. She and her husband were not related. He is a stenographer in a government department and in the evenings he has a business where he practices homeopathic medicine. Financially, they are stable and there is no hardship as such. Her husband has a very supportive family that lives in the same town.

Naeem started going to Fatima-I-Jinnah School a year ago and, after few months, Bilal and Hina joined him at there. Nadia is a very aware and conscientious mother. She spends at least four days a week with her children at the school. In fact, she helps the teacher with the other children.

Seema:

Seema is a 46-year-old Sindhi mother. She has completed 8th grade and is not employed outside of her home. She has been married for 25 years. She has six children – four daughters and two sons. Their ages range from 8 to 23 years. Her youngest, Sadat, is disabled. His disability was detected when he was a few months old.

The government pays the rent of the upper portion of the house where Seema and her family live in Islamabad. This house has three bedrooms. Her husband is the Deputy Director General of the Federal Bureau of Statistics. The family has been transferred to areas inside and outside of Pakistan by the government several times. Most of their family lives in the province of Sindh. She and her husband have regular contact with their siblings; however, the children are not very keen about keeping in touch with the extended family. Seema married within her family. The family is considered well educated and well off. All three of the older daughters are in the final years of M.D., M.S., and B.S. degrees respectively. The younger children are in school.

I observed that the daughters help with household chores and one daughter, in particular, takes the responsibility of providing care to Sadat. The atmosphere of the house was very cordial, warm and democratic. Every child had a say during the interview. Sadat is enrolled in the Fatima Jinnah School. He was diagnosed with Down's syndrome. Sadat's siblings were very protective of him. In fact, they want him to be independent but do not give him an opportunity to act independently. They reinforce negative or helpless behavior for different reasons. First, they want to help him out by doing things for him because they love him. The other reason is that, since they are all very busy pursuing higher education, in many cases it is faster for them to perform a task rather than wait for him to do it. Then, they can get on with their own assignments.

Shabana:

Shabana is a 38-year-old mother with six children. She has a primary education and has been married for 20 years to her cousin. She has one son and five daughters. Their ages range from 6 to 18 years. Her child with a disability is the youngest daughter, Shazia.

Shabana and her family live in the servant's quarter of a house in a well-to-do neighborhood. Her oldest daughter works for the people who live in the main house. A country cousin also lives with them and works as a driver for the master of the house. Shabana's husband works for the postal service in the Secretariats. They live in one room with some open space in an upper level quarter.

The family owns a house in the outer skirts of Islamabad, and moved into this quarter so that Shazia could go to school. They are landowners in a village not far from Islamabad. All their food supplies, such as, milk, wheat, lintels and sugar, come

from their lands in the village. Their extended families live in the village. Shabana makes frequent visits to get supplies and to visit.

Shazia is enrolled in Ibna Sana School. She is a very pampered child who is adored by everyone. She receives total attention from the family and the people who lives in the house. She participates in household chores and when she pretends to be a teacher, everyone participates in her child's play. According to Shabana, Shazia was exposed to 'saya' in her childhood, which was why she had difficulties in school.

Tuba:

Tuba is the 33-year-old mother of three children. She is illiterate and is not employed outside of her home. She has been married for 18 years to her cousin. Her children, all boys, range in age from 12 to 16. Her youngest son, Taqi, is disabled. His disability was recognized when he was four months old. Tuba said she could do nothing about it at the time because she was also sick.

Tuba and her family live in an apartment provided by the government. It is on the third floor, in the same block where Mona lives. Three other relatives, a child and two adults, also live with them. The relatives who are living with them are there to get an education. Tuba's husband, who is very proud of his post-graduate degree, works as an accountant for the post office. The family is from a village and retains very strong bonds to relatives and the land.

Taqi is enrolled in Ibna-I-Sana School. Tuba considers Taqi to be a 'faqeer', as his grandfather and his granduncle were in an earlier generation. It is believed that God listen to faqeer prayers. For that reason, people come to faqeers to ask them to pray for them. A faqeer prays on behalf of people and also may give them indications about what will happen in the future. If their wishes are fulfilled, people reward the faqeer handsomely. Tuba gave me an example of this. She told me of an incident that had recently taken place when a family member came to Taqi. He had asked Taqi for a son. Taqi told him that he would soon father a son. Later, in the year the man's wife had a son. He was very happy and rewarded Taqi.

Zula:

Zula must be in her mid 40's, she does not remember ages. She is illiterate and not employed outside of her home. She has been married about 26 years. She is a second wife. She has three sons of her own and raised three stepchildren. The stepchildren, two sons and a daughter, are older. Her own children's ages range from 16 to 25. Her middle son, Zahid, is disabled and is about 18 years old. His disability was detected after the age of one and Zula believes that he was poisoned by the glucose that was given to him when he was very dehydrated. Zula's husband has just retired and they live in government quarters on the far side of town. The older children have married and moved away. Zula still grieves about the separation.

Zahid is enrolled in Fatima-Jinnah School. The family seemed dissatisfied with the school policies and not being able to get straight answers from the administration regarding Zahid's progress and future plans. They have frequent contacts with their extended family, who are very supportive. They think that Zahid is very fortunate. They also reported that the neighbors were good to Zahid and to the family.



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October 27, 1999

Ms Saira M. Zaidi
3089 Bramble Drive
Reno, Nevada 89509
U. S. A.

Dear Saira:

The Social Work Ethics Review Committee (SWERC) has reviewed and approved the following research proposal:

“Efficacy of Mothers Who Bear the Burden of Care in Bargaining for a Higher Status as Women:
An Ethnographic Study”

by Saira Zaidi

October 27, 1999

The above proposal has been placed on your student file along with a copy of this letter. Please note that you are required to submit any changes to your research from hereon to SWERC for review and approval.

This approval by SWERC assumes that the above research study will not be funded. Note that Section 2.5.2.2 of the *University of Calgary Policies and Procedures for Ethics of Human Studies* requires SWERC to forward any “proposal that is funded from any source internal or external” to a University-level ethics committee.

All the best with your research efforts.

Sincerely,

Margaret Williams

Margaret Williams
Chair, SWERC

MCW:iah

cc: Dr. M. Williams, Supervisor